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Merton Carer Assessment Audit

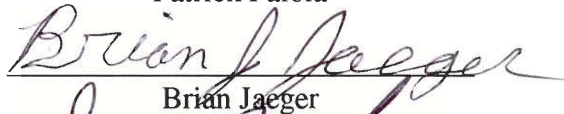
An Interactive Qualifying Project Report
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Abstract

The Carer Assessment IQP evaluated the effectiveness of the recently implemented carer's assessment process for the London Borough of Merton's Housing and Social Services Department. Using questionnaires and focus group sessions aimed at carers and social workers, we analysed the assessment, its implementation, and its effect on the carers. We reviewed the public knowledge of the process and the perceptions of social workers, and then made recommendations as to how a revised assessment could improve carer confidence in Social Services.

Executive Summary

What is the carer's assessment? Do carers in the Borough understand its importance? More importantly, do social service workers realise its significance and are they able to make sense of the provisions available for carers?

Imagine you are a carer. Is Social Services capable of helping you? What assistance will they be able to provide? Now, imagine you are a social worker. How can you properly analyse the needs of the carer? Is the carer's assessment asking the right questions? Should Social Services employ dedicated carer's assessment staff to perform assessments?

Amidst all of these questions, one inference comes to mind: the lack of knowledge. This is one conclusion at which we arrived after performing our analysis. Carers and social workers alike have many unanswered questions, and this is the primary reason the assessment may not be working as well as previously intended. In many cases, where it appears as though the assessments are being properly executed, it may be possible that carers (and social service workers) are misunderstanding the goals surrounding the carer's assessment.

In our investigation, the main objective was to determine public understanding of the revised assessment process introduced in November 2001. In order to accomplish this goal, we identified carers in the region, conducted interviews to determine their perception of, and need for, the assessment process, and determined the extent to which they intended to utilise community care. In addition, we spoke to social service providers to determine how effective they have been in addressing the needs of carers in their district, and sat in on an assessment to better understand how assessments are currently conducted. We then compared the results of our studies to find possible sources of carer apprehension towards the assessment process.

At the conclusion of our study, we analysed our findings, drew up recommendations for future work and delivered our results in a formal report to the Merton Social Services Department and to the Worcester Polytechnic Institute. The following major points can be ascertained from the report:

- More than 50% of carers we contacted during the course of our research were not familiar with the carer's assessment.
- Increasing public knowledge about the assessment process can benefit all carers and social workers in the community by providing an environment where people are aware of the capabilities of Social Services and the services provided.
- Delivering information to carers via direct telephone calls or post and organising training sessions for social workers will improve understanding and proper utilisation of the carers' assessments.

To go about forming these conclusions, we have made an effort to contact all parties involved in dealing with carers and the carer's assessment: carers, social workers and voluntary organisations. To simplify our data gathering and analysis slightly, we decided to concentrate our research on the carers of the elderly. The reasoning behind this was two-fold:

- The elderly make up the majority of the cared-for population in the Borough.
- It would have been much more difficult to discuss certain issues with other types of carers, such as carers of mentally or physically disabled persons.

This decision was finalised in the early stages of our research and although we hoped that the opinion of the carers in this group would provide us with an approximation of the views shared by most carers in the community, we recognised that carers for the elderly might be different in some respects from the broader caring population.

After having the design and content of our questionnaire for carers analysed by social workers and the Data Protection Officer for LB Merton, we sent them out to 198 carers of elderly people. This list of persons was obtained through our contacts at Carers Support Merton. This survey was delivered to twelve carers of elderly people suffering from dementia and thus allowed us to interpret the final results of the survey more critically. In addition to the mail-out questionnaire, our group was able to obtain a list of about 120 carers from the Gifford House, of which nearly 80 were contacted to complete a telephonic survey (of this number, only 41 respondents answered the questions). The major questions that we wished to have answered through the use of these surveys were:

- *Is Merton providing adequate assistance to carers in the Borough?*
- *How well are the assessments analysing the needs of carers?*
- *What more could the Borough do to help its carers?*

The results we were able to gather from these carer queries seemed to cover both ends of the spectrum. As we found with the telephone interviews, 23 of the 41 respondents were not familiar with the carer's assessment. Another seven carers felt that Social Services would not be able to help them or relieve them of their duties in any way.

In an effort to analyse the views of social workers with regards to carers and the assessment, we conducted a focus group with social workers from the Gifford House. This meeting proved to be highly successful as we were able to cause them to continue discussing the issues surrounding the carer's assessment even after the meeting was over. Many looked at the assessment procedure in a new light and were able to grasp flaws and articulate comments that they normally overlooked when actually performing the assessment. Key issues raised during this session were:

- Possible flaws with the carer's assessment form (carer's date-of-birth collected for no apparent reason, the Borough's definition of 'carer' could be easily misunderstood).

- Concerns regarding the training social workers were given with respect to the assessments and the guidelines that the Carers and Disabled Children's Act 2000 provided.
- Questions over the handling of closed cases and situations where the cared-for or carer passed away.
- Discussion about the employment of dedicated assessment staff.

Lastly, our group interviewed personnel at three local voluntary organisations: Merton MIND, Crossroads, and Carers Support Merton. By conducting these discussions, we were able to understand how such organisations provide for carers and why some carers tend to prefer such organisations to Social Services. We have learned that:

- Many of these organisations offer services to a small group of carers, such as Merton MIND, which looks after carers of elderly people suffering from dementia. This enables them to hold social functions and consultation sessions for their carers and to provide care on a more personal level.
- Such organisations are well known in the community because their public relations and advertisement schemes usually outweigh efforts put forth by Social Services.
- Clients are usually not charged for services and, therefore, there is no need for detailed assessments of personal financial information, which many carers find intrusive.
- Typically, carers of older people tend to be elderly themselves, who were raised in a period when laissez-faire thinking was prevalent. As such, many are hesitant to seek government assistance through Social Services.

However, not all carers are pleased with the results of the voluntary organisations. Some concerns were raised regarding the frequency of the assessments, where carers felt they were not properly reassessed whenever their needs or circumstances changed. Others refused assistance because they felt it would mean they were admitting that they were incapable of continuing care for their loved one.

Based on these findings, we formulated recommendations for the Borough to build upon in the near future. These can be highlighted as follows:

- *The dispersion of knowledge is vital in pushing carers to utilise the services offered to them.* Making the public understand provisions such as the Cross-Borough Protocol will enable them to be more receptive of Social Services and its workers. Information can be passed from Social Services to carers by word-of-mouth, newsletter, post, or social worker; all are viable methods of spreading knowledge.
- *Carers are familiar with some voluntary organisations and are pleased with the services they receive there.* Sometimes they make use of such organisations when they feel Social Services will not be able to help them or when they are seeking an alternative channel of assistance. Social Services should continue to work in

conjunction with these organisations because they help balance the community caring load, thereby freeing social workers to attend to other commitments.

- *Social workers are not always comfortable with the level of knowledge they have about the assessment and the provisions available, such as the Cross-Borough Protocol.* Organising training sessions for staff to improve their understanding will enable them to work well with carers, as they will be able to better suggest and cater to carer's needs.
- *The carer's assessment could be restructured to be shorter and more efficient.* Some questions (such as the one pertaining to age) could be reworded or removed altogether. This may lead to a less taxing assessment form and saves social workers from having to keep track of unused data. A well-developed assessment form also makes it easier to analyse the carer's needs when their circumstances change.

The implementation of such suggestions should bring about dramatic changes in the way the assessments and the available services are understood and, therefore, utilised. It will enable social workers to perform assessments more efficiently, without need for analysing redundant data, and will allow both Social Services and carers to communicate more effectively. The 'lack of knowledge' will no longer be a problem, and Merton Social Services can go back to doing what it does best – providing its citizens with assistance.

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Table of Contents

ABSTRACT	I
EXECUTIVE SUMMARY	II
ACKNOWLEDGEMENTS.....	VI
TABLE OF CONTENTS	VII
1 INTRODUCTION	1
2 LITERATURE REVIEW	3
2.1 Introduction	3
2.2 Caregiving.....	4
2.3 Community and the Caregiver.....	5
2.4 Provisions for Caregivers and the Cared-For.....	8
2.5 History of Carers Assessments.....	9
2.6 Carers Assessment Procedure.....	11
2.7 Carer Assistance in the UK	12
2.8 Voluntary Organisations	13
2.8.1 Crossroads	13
2.8.2 Carers Support Merton	15
2.8.3 Merton Mind	17
2.8.4 Other Services	18
2.9 Conclusion.....	19
3 METHODOLOGY	20
3.1 Overview	20
3.2 Methods Specifications	20
3.2.1 Meetings and Preliminary Data Collection	21
3.2.2 Social Workers Focus Session	22
3.2.3 Assessment Sit-in	23
3.2.4 Voluntary Organisation Interview	23

3.2.5	Carer Questionnaire.....	24
3.2.6	Telephone Interviews	27
3.3	Conclusions	28
4	RESULTS AND ANALYSIS	29
4.1	Profile of Carers in Merton	29
4.2	Services for Carers.....	31
4.3	Social Services.....	31
4.4	Voluntary Organisations	33
4.5	Carer Assessment Process	38
4.6	Interviews of Carers (Telephonic and postal surveys).....	39
4.6.1	Carers Age versus Gender	40
4.6.2	Carers Age versus Employment	43
4.6.3	Carers Age versus Health	47
4.7	Carers' Requests for Social Services	52
4.8	Communication Conflicts with Social Services	53
4.9	Cross Borough Problems	58
4.10	Social Worker Interviews	59
5	CONCLUSIONS AND RECOMMENDATIONS.....	62
5.1	Introduction	62
5.2	Profile of Carers in Merton.....	62
5.2.1	Carer Anxiety	62
5.2.2	Multiple-Borough Difficulties.....	63
5.3	Services for Carers.....	64
5.3.1	Service Recommendations from Carers	64
5.3.2	Informal Services	64
5.3.3	Voluntary Organisation Involvement	65
5.4	Carer Assessment Process	66
5.4.1	Introduction of Dedicated Assessment Staff	66
5.4.2	Social Services and its Public Visibility.....	67
5.4.3	Comments on the Assessment.....	67

5.5	Room for Improvements.....	68
5.5.1	Network of carers	68
5.5.2	Development of website.....	68
5.5.3	“Care Plan” for carers.....	69
5.5.4	Improvements with SOSGIS	70
APPENDIX A - CARERS MAIL-OUT COVER LETTER		71
APPENDIX B - CARERS MAIL-OUT QUESTIONNAIRE.....		72
APPENDIX C - CARERS TELEPHONE INTERVIEW QUESTIONS		77
APPENDIX D - SOCIAL WORKER INTERVIEW QUESTIONS		79
APPENDIX E - MEETING MINUTES.....		80
APPENDIX F – CARER ASSESSMENT PROTOCOL		90
APPENDIX G – CARER ASSESSMENT FORM		93
APPENDIX H – CARER DEMOGRRAPHS (LB HARINGEY)		97
GLOSSARY		99
REFERENCES		101

Table of Figures

Figure 4-1 Carers living arrangements with respect to the person they care for. An outside carer is one who does not live with the cared-for, while an inside carer shares a home with the cared-for.....31

Figure 4-2 Ages of all the carers who responded to our telephonic interviews.41

Figure 4-3 Gender ratios that we recorded broken down by age group.....42

Figure 4-4 Hours of care provided by carers in each age range.44

Figure 4-5 Employment status of the surveyed carers.45

Figure 4-6 Health problems reported in telephonic interviews. This chart does not represent the entire range of medical concerns, but for our purposes it clearly indicates the need for taking the carer’s health to be taken into account when performing a needs assessment.47

Figure 4-7 Approximate ages of which a number of specific health issues have been reported. For simplicity, some health categories such as ‘Serious’ have been generalized to cover a broader range of specific issues.....48

Figure 4-8 Hours of weekly care provided by carers with a number of different health problems. With the carer’s age not a factor, note the concentration of carers with health problems continuing to provide 40+ hours of weekly care.50

Figure 4-9 Percentage of carers who had previously been assessed.57

Figure 4-10 Preferred methods of Social Service communication for carer assessment ..58

1 Introduction

The Social Services group in LB Merton works with registered carers to provide services and assistance to those who require it. Evaluations of this partnership have shown that carers are not utilising the assistance to its fullest extent. It remains to be seen if a newly implemented assessment process is properly analysing the needs of its carers and whether carers are satisfied with the results of the assessments.

In 2000, Parliament enacted the Carers and Disabled Children Act to give local authorities the power to assess and meet the needs of carers in their boroughs. The intent of this legislation was to formally recognise the carers as a critical asset to the community and to provide them with sufficient assistance so that they may continue their caring role. This is achieved by assessing the needs of the carer separately from the cared-for, whereas under the Carers (Recognition & Services) Act of 1995, the carer could only seek an assessment when the cared-for was being assessed as well. The carer's assessment has been designed in order to draw together data about the needs of and services required by the carer. Through the use of this standardised approach, social workers will be able to develop individual care plans for each carer, which will cater to both their current and future needs.

Despite an effort to provide services for carers in their own right, many have not utilised Social Services effectively, partly because of a lack of understanding about the provisions. Reasons for this lack of utilisation include the carer's low awareness of support services available, a lack of publicity on behalf of the Social Service department with regards to the assessment procedure, as well as the carer's unwillingness to come forward to receive assistance.

Our main objective was to determine the effectiveness of the new assessment process introduced in November 2001. In order to accomplish this goal, we identified carers of elderly people in the borough of Merton, conducted interviews with social workers, performed telephone interviews, and mailed questionnaires to carers in order to determine their understanding of the assessment process and examined the extent to which they intended to utilise community care. Even during the early stage of our contact with carers, we began to take note of the various subpopulations of carers: those that had been assessed, those who had turned down assessments, those who had relied on the voluntary sector and others who were unfamiliar with the process altogether. In addition, we spoke to Social Service workers to determine their effectiveness in assessing and addressing the needs of carers in the district. We then compared the results of these examinations to find possible sources of carer apprehension towards the assessment process and looked at reasons the process may not be performing as well as it is capable.

At the end of our project, we presented to our liaisons a report of our findings detailing what we thought were the main issues addressing Social Services at this point in time. The report included thorough recommendations to Social Services about: its relationship with carers, resources available to social workers, additional service ideas, and how best to organize the new data they get from carers.

2 Literature Review

2.1 Introduction

National governments around the world have noticed that care giving has been steadily increasing, and in order to assist this growing group, governments have taken measures to become more involved in providing assistance to them. Many societies have created social service organisations, which provide a more planned and developed approach to supplying time, money, and resources. In areas where government assistance is not available, many communities rely on voluntary or non-profit organisations to fill the void created by the absence of government-funded service in their respective environments. In communities that are fortunate enough to have both government and voluntary services working together to provide a range of assistance to those in need, the supplementary aid that is offered can be very beneficial. In many cases, a social services council in the region takes responsibility of overseeing the actions performed by voluntary organisations and the services received by carers.

Social Services helps manage these various needs by providing aid to various groups, such as the elderly, the disabled, mentally challenged, children and caregivers. Since the services provided are usually widespread, social service departments often work in conjunction with many other government agencies, local housing departments, employment agencies, education services, and the criminal justice system. The goal of social services is to provide those people in the community with support, both physical and mental, depending on their circumstances. Providing for caregivers is one way that helps Social Services meet the diverse needs of the people it works with.

2.2 *Caregiving*

Caregivers¹ are volunteers, usually family members or friends, give up their time to provide assistance to those who are elderly, disabled, or dependant on others. Many carers live with the person they care for, but a few look after someone who lives independently. In some cases, the carer is a person under the age of eighteen who is looking after a parent or grandparent². Sometimes, they are known as 'informal carers' because they look after someone without pay or financial reward. Their responsibilities include taking care of basic household chores or attending to the cared-for individual's personal needs. Caregivers play a vital part in the lives of the person they are caring for. They are with them for many hours a week and help the person through the ups and downs of life. In many cases, the caregivers group consists mainly of women aged forty or older, who tend to be the primary carer in a family when there is more than one person caring in the household (National Strategy for Carers, October 2001).

Care giving can be, at times, a great burden and source of stress for many carers, who frequently suffer from ailments such as depression from overwork and lack of sleep. Sixty-one percent of significant caregivers (those providing more than 21 hours of care a week) have suffered from depression, and such caregivers usually do not receive consistent help from other family members (Family Caregiving Statistics, 1998). Lack of sleep has also been shown to adversely affect the caregiver (Stern, Reuters Health, 7 January 2001). Studies have shown that having the ability to talk to someone else, such as a physician, about their feelings lessens the caregiver's emotional stress (Study: Physicians' Empathy Can Ease Caregivers' Depression, March 2000).

¹ See glossary: caregiver.

² See appendix: Young Carers.

These examples of the adverse effect of care giving emphasise the great need of support for a group of individual who serve the community invaluable by taking responsibility for another, often putting their own lives on hold. As many carers are still below the age of retirement they often must give up work with out pension or social security benefits to fall back on. This sudden lack of financial stability coupled with increased responsibility of causes draw with in themselves and become social isolated as they do not be viewed as pitiful or incapable by friends or family by asking for assistance or sharing their problems with someone who dose not understand their situation. This leads to further stress on the carer which has been linked to causing more serious health issues.

Despite this strain there has been no drop in the number of persons who take up the care giving role each year. This raises the question as to why so many people choose not only take up, but to continue doing an activity that is known to have such adverse side effects. One commonly accepted reason is the feeling of responsibility to the cared-for but there maybe additional factors that play into this issue altruistic behaviour. Some medical professionals have begun to study the effects of stress on the human body. One finding of particular relevance to carers is that “stress is believed to have and addictive quality... those leading busy lives with high levels of responsibility can become accustomed to living this way and may find it hard to let go of their responsibilities” (Working with Carers p.45).

2.3 Community and the Caregiver

Care giving may at first appear to be an individual task; however, communities have come together to provide group oriented services. Even given this, nearly 85% of

caregivers tend to not seek outside assistance (Kaplan, November 2001). One of the main reasons caregivers do not use Social Services or other voluntary organisations is because they don't view themselves as carers. Many feel that cultural or family responsibility alone is reason enough to care for someone – they are not aware that they can be recognised as registered carers and can have the opportunity to receive services from their council. Others refuse to accept the use of the term carers, sighting that it implies their caring role is an addition burden rather than a part of their regular responsibilities (Working with Carers p.12) Another reason many don't seek outside assistance is because of conflicting issues with the cared-for person, such as problems with having someone else come in to take care of them (respite care). This affects the carer, because over time it makes the cared-for person psychologically dependent on their care, and any change will adversely affect the caring relationship.

Fortunately, opportunities such as breaks³, sitting services, and residential homes exist to provide the caregiver and the cared-for with the ability to maintain their normal state of life. The establishment of community centres have become more commonplace. These centres are responsible for providing an environment that is less isolated than the homes in which many caregivers and cared-for people live in. They also provide the ability to communicate with others who may be in similar situations. Support groups provide another method of education and give the carer the ability to network with others having similar responsibilities (Tips for caregivers, 2001).

Time is an important factor to caregivers: the time they get to spend with the person they are caring for is an essential part of their lives. Every time Social Services provides aid or other forms of relief to the carer, the logistical aspects of the aid process

³ See glossary: break.

take time away from the caregiver, the cared-for person, and the social worker. One way in which the community has helped this situation is by making an effort to link services together, so that caregivers and cared-for people get what they need in a reasonable amount of time. For example, hospital visits and stays for a person in care are jointly operated by Health Services and Social Services so that the interaction between the groups is almost transparent to the carer in terms of time and efficiency. When it is time for the cared-for person to be discharged back into the care of the carer, there is constant communication between the three parties: Social Services, Health Services, and the carer, so that everything runs smoothly (Being a Carer, June 1999).

In addition to traditional methods, technology has also proved to be highly effective in reaching the needs of carers around the world. The Internet provides a nearly limitless supply of information for social service workers, caregivers, and cared-for people, although finding reliable sources can be a problem. The medium supplies a way for all groups to learn from the experiences of others and also a manner through which to share their own ideas. Through the use of online bulletin boards, such as the one found on the Princess Royal Trust Group's website (carers.org), caregivers are given the freedom to voice their opinions and to question experts. The Internet also provides a global information portal of sorts by giving caregivers and cared-for people access to information about their illnesses and treatments. This kind of primary knowledge, although sometimes unreliable, is nonetheless useful, especially in situations where the person is not in direct contact with an expert, such as a physician.

2.4 Provisions for Caregivers and the Cared-For

To provide for the needs of both caregivers and cared-for people, communities employ many resources such as financial relief, care organisations, housing projects and volunteer services. While some services are fee-based, many are offered free to the individuals in the community, through the use of volunteer activities. Such services include transportation programs, home health care⁴, meals programs⁵, cleaning and yard work services, senior centres, and day-care facilities (“Because We Care: A Guide for People Who Care”, October 2001).

Among the most widely available and frequently used services include transportation and meals services. Transportation services are especially important to older people with limited mobility. Transportation gives them the opportunity to visit their physicians, go to the pharmacy, and attend to daily activities. Many public transit systems provide various means of accessibility in order to assist persons with physical disabilities in going about their normal lives. Those who participate in community meals programs are given the opportunity to socialise, to receive proper nutrition education, and to take part in other activities. In the event that individuals are unable to leave their homes due to the nature of their disability, special home-delivered meal programs are available to provide for them. Housing facilities provide safe environments where persons can take part in various group activities that promote healthy lifestyles and are offered the chance to socialise with different people.

Many employers also provide tax breaks and on-the-job aid to those involved in the caring process. Examples of this include modified pension plans and investment

⁴ See glossary: housekeeper.

⁵ See glossary: meal-delivery service.

opportunities for employees taking on a caring role at home. Some employers provide caregivers the ability to work either full- or part-time and give them emergency family leave options, which can be either paid or unpaid. Other forms of assistance to the carer include: help lines, employee-assistance programs⁶ and support for informal networks of carers, all of which deliver to caregivers, information that is otherwise hard to come by. Employee assistance programs are generally set up by the business that the carer works for. These programs can be a set of general provisions, or something more catered to the carer's individual circumstances. The services provided by an employee assistance program range from the ability to use the phone at any time to emergency leave opportunities.

2.5 History of Carers Assessments

The Social Services Department provides people who receive care with an assessment. After the social worker assesses the needs of the cared-for, they are able to provide services and aid to the individual through the use of a care plan. Until recently, this assistance was focused on the cared-for individual, making no allowances for the carer's needs. In 1986 the Disabled Persons Act was passed, making it the duty of the assessor to have regard for the ability of the carer to continue providing care to a disabled person. This legislation provided an assessment of the carer's ability to continue their caring role but did not provide for services to the carers in their own right.

In 1995, the Carers (Recognition and Services) Act (CRSA) allowed for carers to request an assessment of their ability to continue their caring role irrespective of the condition of the cared-for. This act only allowed for the carer's assessment to be taken

⁶ See glossary: employee assistance program.

into account when determining the level and type of services to be provided to the cared-for and did not grant services to carers in their own right. The CRSA was improved upon in 2000 with the passing of the Carers and Disabled Children Act (CDCA) that now allowed for a carer to be assessed independently of the cared-for. The act enabled local authorities to make direct payments to carers for services that met their own needs (Community Care Assessment and Care Management Procedure, chapter six, section N, pp 6.11 & 6.12).

This series of legislation was triggered by growing concern raised by carers' self-help groups and carers' advocacy organisations who were concerned that carers were not being duly recognised for the services they provide to their community. Estimates have shown that carers save the government approximately £34 billion a year on health care costs that would otherwise be required to place all the cared-for individuals in care facilities ("Millions more carers will be needed", September 2001). This estimate indicates the magnitude of care that carers were providing without financial assistance until the CDCA legislation was passed.

Since that time, the Housing and Social Services Department in LB Merton has been developing strategies for conducting such assessments and for determining levels of aid to provide to carers. Until November of 2001, Housing and Social Services did not have a formal process for conducting these assessments, which left social workers to conduct assessments without standards for determining needs. The process was then standardised in November and now must be reviewed to determine whether the current assessment procedure is operating to the satisfaction of all parties (Community Care Assessment and Care Management Procedure, chapter six, section N, pp 6.11 6.12).

In the absence of a national standard for carers' assessments as well as the relatively short time since assessment began in LB Merton, it is critical that the Housing and Social Service Department be able to quickly analyse the effectiveness of their own methods. The level of carer satisfaction with the assessment provisions is of key interest to Social Services. If carers are unable to understand the process or unwilling to be assessed, the process may need to be revised to account for such drawbacks.

2.6 Carers Assessment Procedure

Under the current Community Care Assessment and Care Management Procedure carers in LB Merton are now authorised to receive assessments of their own needs leading to the development of a carer's support plan contract with Social Services. According to current procedures these assessments are to be conducted at the request of the carer regardless of whether the cared-for is also being assessed. The assessment is to focus on the needs of the carer, specifically regarding those areas listed in A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children's Act 2000 published by the Department of Health (Community Care Assessment and Care Management Procedure section 6.13-6.13)⁷.

It is advised that, though carers must request assessment, all persons who approach Social Services inquiring about their role as a carer be informed of their right to request such an assessment even before eligibility has been established. If an assessment is declined by a carer this fact must be recorded and included in the care/service plan for the cared-for along with a reason if it can be determined (Community Care Assessment and Care Management Procedure section 6.12). Carers have the option of conducting their

⁷ See appendix F

own assessment or to have a social worker perform the assessment. It is crucial that the carer be able to fully understand the results of the assessment and what services are being offered to them, for this reason carers may have their assessments reviewed by council if the social worker's explanation is not sufficient.

Once a carer's support plan has been created and signed by both parties it is the duty of Social Services to continue monitoring the contract to ensure that services utilised fall within the contract. In addition to this monitoring periodic reviews are to be conducted beginning no later than the 12th week of services to ensure that needs are being sufficiently met or to deal with any changes in need (Community Care Assessment and Care Management Procedure section 9.4). Carers may also request to be reassessed at any time if they feel that their current contract is not satisfying their needs.

A standard form is to be used by the primary assessor when conducting a needs assessment⁸. If necessary additional assessments may be conducted regarding financial status, assessments of risk, or any other special medical assessments as determined by the a general practitioner or co-assessors (Community Care Assessment and Care Management Procedure sections 6.1 to 6.9).

2.7 Carer Assistance in the UK

The C&DC Act has shifted most of the federal responsibilities concerning carers into the hands of the local authorities, and has reduced the time and effort it takes carers to access help. The objective of this act is to provide the carers of British communities with physical, mental, and monetary support through government assistance. Faster and easier assessments mean quicker relief and a happier carer community. The recent trends

⁸ See appendix F

in the United Kingdom appear to be controversial. For the time span of 1985-1990, the number of carers in the UK had increased from 6 million to 6.8 million people. However, from 1990-1995 the number of carers dropped to 5.7 million people (“National Strategy for Carers”, October 2001). In an attempt to determine why this occurred, experts in the UK analysed the various trends in the workplace, home life, and health risks to get a better understanding of why such shifts had taken place. The results displayed an increase in the number of women in the workplace, a decrease in the number of women who live by themselves, and an increase in the population of older people. The increase in the number of women in the workplace partly explains the reason there has been a decrease in the number of carers, since most carers tend to be women. In contrast, a community with a higher density of married older people could increase the number of carers in a survey (“National Strategy for Carers”, October 2001).

The national UK legislation passed in the last few years serves as evidence of the government's perception of the importance of carers to the well being of their communities, and, as such, the governments have developed a variety of plans to help carers. These proposals have a tendency to move away from federal control, which has resulted in the localisation of social services. In some cases, governments have sought the help of voluntary organisations such as the Princess Royal Trust Group, Carers National Association, and Crossroads.

2.8 Voluntary Organisations

2.8.1 Crossroads

Crossroads was established in the United Kingdom with the mission to provide carers with a much-needed break or some level of respite care⁹. Crossroads began offering services in LB Merton 16 years ago as a voluntary charitable organisation funded by Merton Housing and Social Services as well as many other charitable grants. In order to provide support in the home of the carers, Merton Crossroads has hired a 22 person support staff to provide proper residential aid to the cared-for. These men and women do not perform a sitting service but rather fill the role of the carer for a few hours a week on a consistent basis so as to develop a comfortable working relationship with the cared-for. All the support staff members undergo continuous training to properly handle and transport the elderly and handicapped. The staff members also provide physical therapy to those in need, as well as toileting and any other service the carer would normally provide, with the exception of administering medication.

This service attempts to help the carer by attending to the needs of the cared-for in the carer's absence. When Crossroads managers are assessing the needs and eligibility of the carer, they attempt to determine which of their support staff best matches the needs and interests of the cared-for so as to make the experience as comfortable as possible. This service allows the carer free time to attend to their own needs with the confidence that the one they are caring for is receiving the proper attention. Other services include a 10-hour over night care session that allows the carer to receive a good night sleep up to 3 nights a week. They also provide weekend breaks every few months to allow carers to attend special events or to go on mini-holidays (Services Provided by Crossroads, 2000). An anonymous person who has made use of the Crossroads' service offers this testimonial: "Crossroads gives me a chance to enjoy a few hours of relaxed quality time

⁹ See glossary: respite care.

with my husband knowing my Father is being well cared-for. Also giving Father the added stimulation of another person to talk to. Thank you very much for this. [sic]" ("Testimonials", Crossroads Association).

Carers are referred to Merton Crossroads by Nurses, Physicians, Social Services, or on a self-referral basis. Upon referral, all carers are assessed by one of the carer support managers to determine their eligibility for and the degree to which respite service is needed. Though Crossroads has a funding contract with Social Services, the provision of assistance to their clients does not require the carer to be registered with Social Services.

2.8.2 Carers Support Merton

Carers Support Merton is a voluntary organisation dedicated to identifying carers in the community, identifying their needs, and finding ways to support the carer so that they may continue in their caring role. The organisation was established in 1992, in response to carers and former carers seeking acknowledgement of their situation; the group is led by former carers. Carers Support Merton (CSM) is the only voluntary organisation in the borough of Merton that provides services to carers of all groups and disabilities, including young carers, disabled carers, and carers of all minority groups. The intent of this organisation is to help carers gain access to support agencies already available to them, as well as to raise awareness among the community of the importance of carers and the need to address carers' issues (CSM Application for Grants Form - Housing and Social Services in LB Merton).

The services provided by Carers Support Merton take three main forms: advice, training, and information distribution. The extent of the provision of advice includes

direct care work with carers to identify and obtain services in the community as well as to promote information advocacy. The training element of CSM is intended to assist carers self help organisation better provide for one another's needs when formal assistance is not available or when carers are unable to qualify for assistance. CSM also distributes a quarterly newsletter that informs carers of ongoing changes in legislation as well as actions being taken to raise the public recognition of the role of carers in the community.

Carers Support Merton is in essence a middleman between the carer and Social Services. They are able to provide the advice to the carer in order to help them increase their awareness of the programs Merton has to offer. They will point out what they feel the carer is eligible for under the laws in the United Kingdom, and they try to make sure the carer takes at least the step to acquire the assistance.

What often happens in the Carers Support Merton will refer a carer to Social Services. They have usually already performed their own assessment; therefore, understand what it is they believe the carers should be receiving. At this point, the CSM worker will often point out that when the cared-for is in receiving their assessment for services that the carer would also like to receive their own assessment for the job that they are performing.

Carers Support Merton would like to see some new programs developed for the disabled people in Merton. There are almost no services in the Borough designed to provide temporary care to younger people dealing with dementia, and adults with mental health problems. These people must rely solely on their carers for the constant attention they require throughout the day. CSM also pointed out that there is no service that can be

called with flexible respite care. According to the CSM staff, this is the most sought after service not available in Merton. (Eve Brimacombe, January 31, 2002)

2.8.3 Merton Mind

Merton Mind is a specialty care organisation that operates a day centre in LB Merton for the elderly with dementia. In February 1993 Merton Mind began running its “Open House” sessions once a week where carers are invited to spend a day with their cared-for at the centre so that they could experience the level of care that the Day Centre staff could provide. In this way Mind is able establish contact and provide assistance to a group of carers who, due to the nature of the people they care for, are generally very reluctant to seek assistance of any kind.

Due to the progressive stages of confusion caused by dementia, the carers of these confused individuals often become socially isolated due to embarrassing, rude, or odd behaviour of the cared-for. The Day Centre offers them an environment where all the carers face similar situations and no one is surprised or turned off by such behaviour allowing for the carers to begin forming new social groups talking openly about their experiences and offering one another support. In addition to social opportunities and Day Centre care, Mind also offers specialty in home respite care with staff specially trained to work with those suffering from dementia.

Mind’s Open House program has been so successful that many couples who begin attending continue right up until the death of either the carer or the cared-for. In the event of the death of the cared-for Mind operates a Next Step program that the ex-carer can continue to attend for six months. This program focuses on restarting life after the

caring role has ended. Mind has found that this program is essential for properly treating ex- carers for the sever depression that often follows the loss of the cared-for.

Following the Next Step program is an organisation run by ex-carers known as Keep in Step that further extends the supporting role of Next Step. Keep in Step meets annually at the Day Centre to remind those who are still carers that they will have a future life to look forward to after their cared-for has entered institutional care or has passed away. As result of the continuing network of support services, Mind has found that their carers and ex-carers have formed a very close social atmosphere that has dramatically improved the lives of all carers involved and made it easier for them to cope with the depression and isolation that is commonly accompanies their unique position.¹⁰(Geoff Spencer/Margaret Crouch, January 29, 2002)

2.8.4 Other Services

Along with Crossroads, the United Kingdom has many other support services specifically designed to aid the carers. There are also many different services provided on a localized level, many with similar programs, such as the ones found in LB Merton. Merton's Social Services department, working in conjunction with many other government and volunteer organisations, has produced a large number of services whose goal is to aid those in the borough of Merton who are less fortunate and require assistance. Merton not only has its own Crossroads Care Support Workers Scheme and Community Care Division, but also a program called Care Connect. It provides confidential, free, and impartial information on the local and national care services

¹⁰ See Appendix D

available (Merton Care Connect, June 2001). All of these services combine to form a large community push behind carers in Merton.

2.9 Conclusion

Because of their critical importance, carers are recognised by Social Services as being at the centre of a community-oriented support plan. Reliance on caregivers works well when members of the local community realise the essential role of carers as service providers, when carers are able to volunteer their time and resources, and when they receive support that they need and deserve. Localisation shows the significant responsibility women hold in the caregiving process and how a community can greatly effect how carers are supported. Because of these efforts, carers are now getting more recognition and support for their tireless labours during every day of their lives. Besides community support, corporations have become a major contributor in aiding the needs of carers. These businesses have begun to launch new programs to address the needs of the caregivers, both in terms of breaks and financial options. In addition, technology has played an increasing role in the caregiver support network, allowing more people to share information and their opinions, which are moulded out of their personal caring experiences. Care giving used to just be about taking care of your loved one or friend, but now it is an established part of many communities, linking Social Services, Health Services, and other agencies to make the caring process benefit all those involved.

3 Methodology

3.1 Overview

The task our IQP team has undertaken is to provide Merton's Housing and Social Service department with our findings on the new assessment process, implemented in November 2001. To do this, we have spoken with carers, social workers, and various voluntary organisations in Merton. Additionally, we have contacted carers in the community by distributed questionnaires and conducting telephone surveys to in an attempt to explore the level of understanding carers have about their rights. We have collected information on the effectiveness of the assessment process from the carers' standpoint. With this collected data, and with our understanding of the carer's assessment, we were able to draw some conclusions as to where the Borough might do more to help carers in the community. This data collection process utilised the methods described in the following section.

3.2 Methods Specifications

The task of researching, collecting data, and compiling results was divided into three phases. These phases have been divided between interviewing Social Services personnel, interviewing members several voluntary organisations, and then questioning carers themselves. The interviews with Social Services were conducted in order to determine the specific manner in which the assessments are administered. We then contacted the voluntary organisations so as to obtain a better understanding of the most common services provided to carers as well as to obtain outside information on the carer experience and how Social Services is viewed publicly. Finally, contact with carers was

made through a series of telephone interviews and mail-out questionnaires, which were sent out to a sample group of carers of the elderly.

The carer interviews and questionnaires were used to establish whether the carers fully understood or were even aware of the new assessment procedure and the services it entitled them to receive. The telephone interviews were combined with the mail-out questionnaire in order to gather a larger sample of carer responses focusing on their decision to be assessed in their own right, and how they view the assessment process in terms of the responsibilities to the ones they care for.

3.2.1 Meetings and Preliminary Data Collection

We have spoken with many of the staff members at the Housing and Social Services office in order to become familiar with the social workers, and the way in which the assessment is administered. In doing so, we were able to compare and contrast the methods Social Services now uses to assess carers with those methods that they had previously used in carer assessments.

It was suggested by Merton personnel that, although we had researched the subject, we might benefit from more personal exposure to what it is like to be a carer. In order to gain a more in depth perspective on the caring role and what it entails, we arranged a meeting with Merton Mind – Elderly Service. This organisation runs a day centre for the mentally disabled as well as a weekly meeting on Tuesdays for carers to attend with their cared-for. We sat in on one of these meetings and spoke with carers directly, discovered more about the caring role and the kinds of problems carers face on a regular basis, and obtained a first-hand perspective on what it means to be a carer. Once we had a better idea of the responsibilities carers deal with on a daily basis, we were able

to move onto speaking with carers and their social workers on a deeper and more informed level.

3.2.2 Social Workers Focus Session

To gather views and opinions from a different perspective, we conducted a focus group with a number of social workers from the Gifford House. Our intention was to speak with social workers that were involved with the elderly, their carers, and the carer's assessment. We were aiming to find out how social workers perceived the carer's assessment, the reactions they were receiving from carers and cared-for, and the services that they felt could be best provided by the Merton Council. To achieve the results we were expecting, we familiarised ourselves with other focus groups performed in the past (using examples found in books and on the Internet). We decided to use the most effective parts from some of the sources and arrived at our final model. We started by introducing ourselves and by explaining the topic at hand ("the carer's assessment"). We then executed the discussion by asking one of the questions from our pre-developed list. Occasionally, in an effort to move the conversation along, we mentioned additional comments and questions as a way to lead the group into providing better feedback.

Examples of questions asked include:

- What can Social Services do better?
- How do you feel about employing dedicated assessment staff?
- How significant is the presence of the cared-for when performing the carer's assessment?

Using our laptop computer, we recorded a transcript of all the verbal exchanges during this session (See Appendix *). This information was then used to evaluate the

interpretation and utilisation of the assessments and to analyse the actions Social Services could take to make the assessments more effective.

3.2.3 Assessment Sit-in

In order to understand how an assessment works, we were able to obtain permission to sit-in on a carer's assessment, which a social worker was performing. This proved to be a worthwhile experience as we were able to witness the interaction between the social worker and the carer. Variables that we decided to note include: the presence and interaction of the cared-for, the manner in which the social worker approached each question, and the carer's understanding of the questions asked.

3.2.4 Voluntary Organisation Interview

The voluntary organisations in Merton that provide services to carers in the borough were useful for gaining information pertaining to the needs and common experiences of carers. Programs such as Merton Crossroads and Carers Support Merton are services that are available to all carers and provide various services to the community that aim to help carers manage their lifestyle and responsibilities. Although these services receive financial support from Social Services, they do not require their clients to have previously registered themselves with the latter group. This means that although Social Services has the right to periodically check these organisations to ensure that proper services are provided, they do not have access to the client records of these organisations or to the services they provide each client. We conducted interviews with several of these voluntary organisations in order to obtain a more independent, third party perspective on the amount and type of assistance required by carers and on the

relationship between carers and Social Services. In particular, we interviewed representatives from 3 voluntary organisations – namely, Crossroads, Carers Support Merton, and Merton MIND.

In order to collect this data, we interviewed members of these voluntary organisations who had frequent contact with carers using their services, and therefore, would be able to describe the process by which carers go about obtaining assistance. Our interviews focused on the kinds of services such organisations provide, the most frequently used ones, and the ones social workers have recommended to the carer. In addition, we used these interviews as a method for observing how Social Services operates with external service groups.

Once we had conducted these interviews with the various organisations, we coded our data from each organisation into categories in order to reveal both the positive and negative aspects of the assessment process, the services that these organisations currently are offering, and their perspectives on the provisions Social Services is making available to the community of carers. From these results, we were able to better understand how Social Services is perceived by those outside the system – e.g., carers who have elected not to take advantage of assistance available from the council. This information was used to help explain why some carers are declining assessments despite their eligibility as well as addressing concerns about how well Social Services is prepared to take on the task of carer assessments.

3.2.5 Carer Questionnaire

The carers' perception of the assessment process is of vital importance to our research. To make our data gathering and analysis stages slightly simpler, it was

suggested by our liaison that we focus on the carers of the elderly. The reasoning behind this was two-fold:

- The elderly make up the majority of the cared-for population in the Borough.
- It might prove to be much more difficult to discuss issues with other types of carers, such as carers of mentally or physically disabled persons.

This decision was finalised in the early stages of our research and although we hoped that the opinion of the carers in this group would provide us with an approximation of the views shared by all carers in the community, we recognized that carers for the elderly might be different in some respects from the broader caring population.

We anonymously obtained the names and addresses of elderly carers from Carers Support and sent out questionnaires to 200 persons. Before the questionnaire was posted, we had its design and content approved by our liaison to make sure that the information sought in the survey was appropriate and suitable for the group of carers to whom it was sent. After approval, we had the Data Protection Officer for LB Merton review the content of the document prior to public distribution.

We pre-tested this survey with a small group of twelve carers of the mentally disabled at the Merton Minds facility. As these carers all care for elderly people suffering from dementia, their answers were expected to be similar to those we anticipated from the broader population, at least in respect to their caring roles. The information we were interested in obtaining from this group centred on the difficulty of the survey, as well as whether the answers given on the survey would reflect a full understanding of the questions asked. This information allowed us to interpret the survey

results more critically. Due to the limited variation and small number of carers taking part in this validation process, the answers given will not be included in the survey analysis other than as a basis for comparison.

Included with our questionnaire, the How to get help if you are looking after someone pamphlet, provided to us by Social Services, explains to carers the effect of the Carers and Disabled Children's Act 2000 that entitles them to receive assessments in their own right. It also defines key words and phrases used by the council so that both social workers and carers alike can understand the meaning and use of the words ('carer', 'eligibility criteria', etc). The intent of this pamphlet was to promote availability of assessments to those carers who might be unaware of these changes in legislation. The inclusion of this document provided a means of spreading knowledge about the services offered to carers by the Borough.

The primary goal of this questionnaire was to determine whether previously assessed carers were satisfied with the response that Social Services has provided. We also aimed to gauge the success of the assessment process and the carer's level of confidence that their needs, once assessed, would in fact be met. Alternatively, if the carer had not been assessed or had chosen not to be assessed, the questionnaire was designed to record reasons for this as well. Those who were not assessed were extremely important in establishing why carers have reservations about participating in the process. For this reason the questionnaire was split into the following three sections: a) basic carer background, b) questions geared towards previously assessed carers, and c) questions relating to carers who had not been assessed.

While examining our results, we obtained useful information about those who have been assessed and those who have not. The manner in which our questionnaire was organised enabled us to sift through the results by categorising the two distinct groups. Categories such as age and hours of weekly care giving were used to determine whether such variables influenced peoples' perception of the assessment process and their willingness to contact and receive aid from Social Services. After gathering the responses from the survey, we evaluated and grouped the answers among those who had already been assessed, those who had not, and those who declined the assessment altogether.

3.2.6 Telephone Interviews

The other half of our carer contact process involved telephone interviews. We obtained a list of cared-for individuals from the Gifford House. From this list of cared-for people, we were able to generate a list of 120 carers and their telephone numbers by cross-referencing Merton's SOSCIS database. Over a period of a week, we rang these carers and asked whether they would be willing to participate in a telephone interview. After talking to the carers who were willing to speak with us, we were able to better comprehend their understanding of the assessment process, the services they make use of, and whether they feel they are receiving enough aid to enjoy a healthy lifestyle while providing care at an appropriate level.

The phone interviews gave us the ability to gather additional information, such as feelings that the carer had that could not be expressed through the questionnaire. Through this process we sought answers to the following broad questions:

- Is Merton providing adequate assistance to the carers?

- Does the assessment process work?
- What more could the borough be doing to better aid the carers?

This information was recorded along with statements made by carers regarding the operation of the assessment process. These statements were highly subjective in nature but, when combined with the questionnaire, provided a basis for a more in-depth analysis of the carer-Social Services relationship and difficulties with the assessment process.

3.3 Conclusions

Following the completion of data collection and the analysis of our interviews, we brought the data together and performed a holistic analysis of the assessment process. This analysis combined the comments, opinions, and statements made by all groups for the purposes of comparing the goals of the current assessment process with the reality of the assessment as it is actually practised. The goal of this analysis was to determine whether the assessment, as it is currently set up, was capable of determining a carer's needs and channelling services to the carer that would meet those needs.

This analysis was provided to our liaison in the form of a report that summarised all the information we gathered and included suggestions on ways in which the assessment could be simplified and carer participation could be improved. All suggestions were aimed at improving the assessment process and communications regarding it, so that all interested parties will be able to comfortably discuss any needed changes in assessment procedures in the future.

4 Results and Analysis

4.1 *Profile of Carers in Merton*

In an effort to focus our research and to complete an in-depth analysis of carers in the borough, we focused on the carers of older people. This population makes up the majority of the carers in the borough, and are easier to reach, because many are retired or work only a few hours during the week.

In terms of borough demographics, we were only able to obtain rough estimates of the number of carers known to Social Services. Through our liaison, we were able to obtain statistical data from a 1999 report on the Borough of Haringey, which we were told has roughly the same population distribution as Merton. Though this information does not directly apply to Merton itself, it allowed us to obtain an idea as to the size of the carer population we were researching.

Haringey reported having 20,870 known carers between the ages of sixteen and eighty-five (See appendix for more information). Of this group, 12.97% were over the age of sixty-five, or retirement age, and nearly fifty-two were over the age of forty-five. This is similar to the data found among the carers with whom we made contact and supports the validity of our analysis. Further support for our analysis is found in this report showing that 58.7% of the carers in Haringey were female and the remaining 41.3% were male.

For clarification purposes, it must be stated that the Haringey demographics do not list the carers in terms of who they care for, so we can not say that these are all carers for the elderly. We had to make another assumption in this case that if our statistical

information was relatively similar to that of Haringey, then a conservative estimate of 60% of carers over the age of sixty-five were ones who cared for the elderly. That means that of the 20,870 total carers, approximately 2,710 can be reasonably assured to be carers for the elderly and that all our following statistical data is based on this assumption, though that number may actually be much higher.

The populations we have used to compile our data included lists of carers obtained from Gifford House and Carers Support Merton, which provided us with 120 and 198 names of carers, respectively. We used the list from Gifford House for our telephone interviews, and the list from Carers Support Merton for the mailed questionnaire. In both lists, we have found that most carers are related to the person being cared-for. Many are husbands, wives or children, which shows that the caring role often falls upon those closest to the person being cared-for. The basis for this argument comes from the number of carers who reported living with the cared-for. Though we did not specifically ask for the relationship between the carer and the cared-for, most carers we contacted mentioned this when questioned about their living arrangements. In a few cases, the carer turned out to be a close neighbour or friend, whose proximity made it easier for them to provide care similar to a level which would be provided for by a family member. Two phone conversations revealed that friends and neighbours of the cared-for undertook the caring role when the cared-for had been discharged from the hospital and there was no family nearby to take care of them.

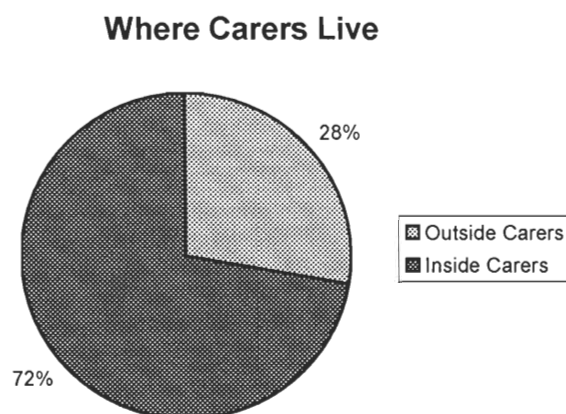


Figure 4-1 Carers living arrangements with respect to the person they care for. An outside carer is one who does not live with the cared-for, while an inside carer shares a home with the cared-for.

4.2 Services for Carers

Communication with Social Services and voluntary organisations has provided us with information about the services offered and about the provisions Merton carers use frequently. This interaction was also advantageous in that it gave us the opportunity to explore the qualifications of people who were performing assessments and dealing with carers on a regular basis. Comparisons between the methods used by social workers to conduct assessments and those used by members of the voluntary sector were used to weigh the advantages of different approaches.

4.3 Social Services

Social Services provides services such as: home care, day services, respite care, and meals to all who qualify. Depending on their financial situation, the person involved may have to pay part of the cost for the services. Social Services uses a financial assessment

to determine these contributions, and conducts these assessments annually. Through the use of the financial assessment, Social Services is able to determine the disposable and allowance income and, therefore, is able to calculate the person's contribution for the services.

Many services "provided" to the carer, are joint services, because they involve the cared-for as well. An example of this is Meals-On-Wheels. When an assessment has taken place, and the carer has stated that they can no longer make meals for the cared-for, the Meals-On-Wheels service can be provided to them. The service directly helps the carer, because they no longer have to worry about making meals for the person they care for, but the service is providing the cared-for with healthy prearranged meals as a result of the carer not being able to cook anymore. Services like day care and respite also involve the carer and cared-for. When a carer is entitled to get day care services, they are basically services for the cared-for, because the carer has made it apparent that they can no longer provide an appropriate level of care during the day. If the condition of the person being cared-for has worsened and the normal chores and other tasks the carer performs on a daily basis has been impeded day care will be provided. So while day care gives the carer, the ability to go out and perform their daily chores, it also provides the cared-for with the appropriate amount of care during the time the carer is away. The same is true for respite care, while the carer is off on a vacation the cared-for is receiving appropriate care in a respite care facility.

Through our research, we have found that there are very few services offered that solely involve carers. This problem has occurred, because Social Services, has yet to secure guidelines and base cases from which to decide what services to provide solely to

carers. Social Services know some of the provisions carers want, but they have not found a standardised way to determine how to deliver these services. It has been discussed, that a carer may need a mobile phone in order to have the ability to constantly check in with the cared-for from anywhere, but Social Services has not come to grips with providing custom need based services as of yet. There is also the question of how and when to use the Carers Support Grant money that Social Services has to provide types of custom services to carers. Addressing these issues will no doubt help Social Services meet the needs and expectations of its clients for the better.

4.4 Voluntary Organisations

Voluntary organisations such as Crossroads and Carers Support Merton provide free carer services. They do not, however, provide the same assortment of services that Social Services provide, and they are far more limited than Social Services as to the number of carers they can assist. Many services offered by the voluntary organisations concentrate on home-based respite service for carers and provide consistent breaks during the day or evening. Some organisations also hold regular consultation visits to discuss issues affecting their clients, and details of these meetings are sometimes made public for the benefit of other carers.

Other organisations such as Merton Mind attend to the social needs of carers by setting up regular group meetings or outings where carers can openly talk about their situations with others facing similar problems. Social Services may not be able to organise social functions for its carers, but this situation highlights the social isolation that can plague many carers.

We have learned that people approach voluntary organisations rather than Social Services primarily because these organisations have made themselves well known throughout the region. Their public relations and advertisement schemes with regard to the services they offer are usually more significant than the efforts put forth by Social Services. This can partially be attributed to the fact that, as volunteer or charity organisations, they must seek funding from the communities they serve as the grants they are given by the local authority do not cover all their expenses. Events such as public fund raisers, campaigning, and lobbying for the rights and recognition of carers go along way in spreading the public awareness of these organisations (Carers UK Annual Report 2000/2001).

Since Crossroads, Merton Mind, and Carers Support Merton do not charge users for their services, their appeal sometimes is greater than that of Social Services. These organisations do not ask for the carer's personal information, but do perform a specialised assessment that focuses on what they are able to provide to the carer. Many carers find such assessments intrusive and may fear revealing hidden assets they had planned to save for other purposes (Moray Holbrook, Crossroads, January 21, 2002). To this end, special techniques were developed to properly perform assessments and social workers must be well-prepared to conduct the type of dialogue that may be required to properly assess a carer's needs. (Geoff Spencer/Margaret Crouch, January 29, 2002).

Some of the most important functions these organisations provide are their information, advice, and referral services. In particular, they strive to alert carers of assistance opportunities that they may not be aware of. Carers Support Merton estimates that they inform the carers of an additional 50% of the programs locally available (Eve

Brimacombe, January 31, 2002). These included referrals of carers to Social Services whenever the need for a carer's assessment existed. One issue that was mentioned numerous times by all three volunteer organisations is that the carers' assessments are not done frequently in order to deal with changes in the carers' situations. Carers Support Merton representatives stated that they often had to request that their client be reassessed; social workers did not always maintain regular updates on the carers' situations and, therefore, were never aware of this situation (Eve Brimacombe, January 31, 2002).

An important issue that was raised in discussions with Carers Support Merton is that many service users, the cared-for, and their carers, do not trust Social Services to deliver helpful services even if an assessment was performed. Some carers did not understand the significance of the carer's assessment, and did not realise that they would gain help for their caring role. For example, carers over the age of sixty five qualify to receive three weeks of respite care, but the borough lacks the facilities to provide respite care to those under sixty-five (Eve Brimacombe, January 31, 2002). Adding to this argument is the view that social workers are becoming overburdened with their growing list of responsibilities and, therefore, the assessments are not given priority during their daily tasks. This means many carers who may have heard of the assessment never receive one, because they are unaware of the steps to be taken in order to request an assessment. Evidence of this increased responsibility is provided in Working with Carers, which states that "A significant change in the assessment process [is the move] from the perspective of the service user to the cared-for and their carer. ... Previously carers would only be assessed if there were obvious problems or risk of a breakdown of the caring system" (p.66)

Carers Support Merton informed us of two main issues that they felt led carers to decline an assessment by the borough. The first had to deal with the group of carers we are focusing on, the carers of the elderly. Typically these carers tend to be elderly themselves and as such, we were told, they were raised in a period where people were taught not to seek government assistance. Pride and independence are more important to the elderly population than to the younger carers who were not raised under the same conditions. The other factor is that many people fear that by seeking government assistance they may be admitting that they are incapable of continuing to care and thus risk having Social Services remove the cared-for from them (Eve Brimacombe, January 31, 2002). This strikes at both the fear of possibly losing someone for whom the carer feels responsible to care for and the fear of being judged a failure. In this way, the assessment may be seen more as an assessment of the carer's ability to continue and not a need for assistance from the local authority.

We used the opportunity to connect with carers via a weekly seminar at Merton Mind which provided a straightforward perspective on the opinions carers have about caring. This group setting facilitated open communication and collaboration which helped carers understand the problems they faced. The session provided us with better, more complete answers to questions about carers and the caring process. However, the group environment also added partiality with regard to some questions we asked because some carers could pick up on ideas previously mentioned by another person. The carers at the open house meeting we attended were quick to point out that they preferred to deal with this volunteer organisation, rather than Social Services. The services at Merton Mind are provided more quickly and consistently. We heard numerous carer accounts of

how difficult it was to get the services the Borough provides actually delivered and then the problems that ensued if the carer was not satisfied. From a practical standpoint this is expected because the number of carers registered with Social Services far out weighs those who use the Merton Mind facility, but that rational did not help to change the way carers at the open house view Social Services. This poor perception towards Social Services carries directly over to the way carers viewed the assessment process.

Through the use of this group meeting, we have been able to gauge the carers' satisfaction with the level of service Merton has provided them. In comparison to what they received from Merton Mind, satisfaction with the Borough's services was generally low. It is important to note; however, that this was a very small group of individuals who were all caring for elderly individuals with dementia and do not represent the wide range of carers Social Services works with. The goal of our attendance at this open house was to seek some insight into how carers view Social Services versus volunteer organisations. Though this was achieved, the lack of diversity among the carers we spoke with meant our observations would have to serve more as a guide for interpreting other carer responses, rather than as the general consensus of all carers for the elderly.

After we spoke with these voluntary organisations we were better able to critically analyse the rest of our data, using the opinions and suggestions put forth by carer advocates outside the Social Service system. As it pertained to the assessment process, these groups and individuals were able to offer their advice on what a comprehensive carer's assessment should contain and what special considerations should be taken into account. This information was used to support our methods for analysing the usefulness of the carer assessment process.

4.5 Carer Assessment Process

In order to understand the objectives of the Merton Community Care Assessment and what it entails, we referred to the Housing and Social Service Department's Care Management manual and discussed the process with social workers within the department. The assessment was designed to meet the needs of and to provide the right services and support to carers. There are two ways in which a carer can go about receiving an assessment. If they chose to receive an assessment when the cared-for is being assessed, the social worker will perform the carer's assessment. If the carer chooses to be assessed, with out the previous knowledge of the cared-for, Social Services will proceed as follows. The initial stage called "First Contact," is a stage used to increase public awareness of the carer's assessment process. In this stage, Social Services distributes information leaflets at various access points for the benefit of the public. The second stage, "Referral," is the stage in which Social Services identifies a carer. A person may be referred by an external source such as a voluntary organisation or a general practitioner and must meet eligibility criteria, which ensure that only the people who need the services most are able to obtain them. The third stage, the "Carer's Assessment" is when a social worker evaluates the carer's needs and takes note of their disabilities.

Following the assessment, a social worker develops a "Carer Support Plan" that provides a set of objectives for Social Services to meet. It is in this step that charges for registration and services are taken into account. The "Care Support Plan" is then passed to the relevant manager(s) by the social worker for recommendation / approval. The plan is monitored by Social Services, and within the first twelve weeks an official review of

the plan and the carer is commenced. After this point, the “Care Support Plan” is reviewed on a yearly basis and offers the carer a chance to comment on the quality of service. At the close of a “Care Support Plan,” which is brought about by either a transfer or end of a caring role, the carer is given the opportunity to provide feedback about the services received.

4.6 Interviews of Carers (Telephonic and postal surveys)

The use of the telephone as a communication medium (as opposed to the mail-out questionnaire) allowed us to ask more descriptive questions, as we could rephrase and clarify the queries as we saw fit. Additionally, we had a greater initial response rate, as we found that once a person answered the phone they were 76% more likely to complete our survey than to decline participation. These interviews also allowed us to record carer testimonials pertaining to Social Services and the carer assessments. Such testimonials were of double benefit, as they were both necessary for our research purposes and of particular interest to our liaisons who requested copies of the testimonials for their own purposes.

After obtaining a list of 120 persons for the telephone survey, we cross-referenced the cared-for information provided with the information in the SOSGIS database to obtain a list of corresponding carers, and then started ringing up carers. We were able to actually speak with seventy-two of the 120 carers. The other forty-eight people on the list were unable to be reached because of wrong number errors, unanswered calls, or situations where either the carer or cared-for had passed away. Of the remaining seventy-two carers, thirty-one declined to take the survey or were not available to take the survey once we finally reach the house and the remaining forty-one carers were willing to

participate. Therefore, we received a final response rate of 57% from these telephone surveys.

After collecting the carer's responses to our interview questions, the answers were recorded in our database in a numerical coding format. Due to a low response rate to our postal survey, we merged the data from both the telephonic interviews and returned surveys when creating the database. Using this database, we began to analyse the results by using simple grouping processes to identify similar answers. We then used more complex queries to find links between responses, such as relationships between age/health and hours of weekly care. This and other comparative data is shown in more detail in the following sections.

4.6.1 Carers Age versus Gender

Our first step in organising our data was to separate the interviewed carers into five age groups (See appendix: telephonic interview and postal questionnaire). Of these five groups, all the carers contacted fell into the last four categories of 26-44, 45-64, 65-75, and 76+ as seen in the graph below. These age ranges were expected as all our carers were caring for elderly individuals, and most of the carers were spouses, children, brothers/sisters, or close friends of the cared-for. As such, they tended to be older people themselves. The information pertaining to the carer's relationship to the cared-for was mentioned by the carer. However, this information was not formally recorded for anonymity reasons.

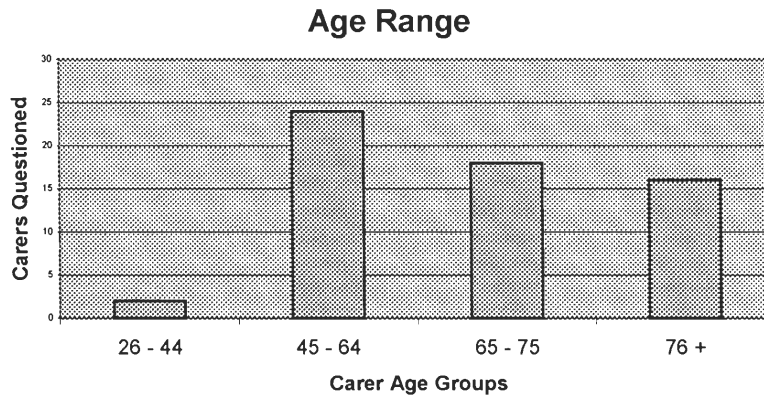


Figure 4-2 Ages of all the carers who responded to our telephonic interviews.

When comparing the number of male to female carers, we found that 40% of our contacted carers were male and the remaining 60%, female. According to our preliminary research, we expected to encounter a greater number of female carers but not necessarily such a dramatic difference. One possible reason for this difference is the small number of carers we were originally given to work with. This may not have been a large enough sample to allow the genders to fully average out. In terms of our original telephone list of 120 carers, the listed names showed 36% male, 58% female and the remaining 6% we were not able to confirm the gender due to unfamiliar or missing names/titles. These numbers are in line with a 1990 General House Survey (GHS) of the UK that showed 43% of carers to be male and 57% to be female (Working with Carers p.28).

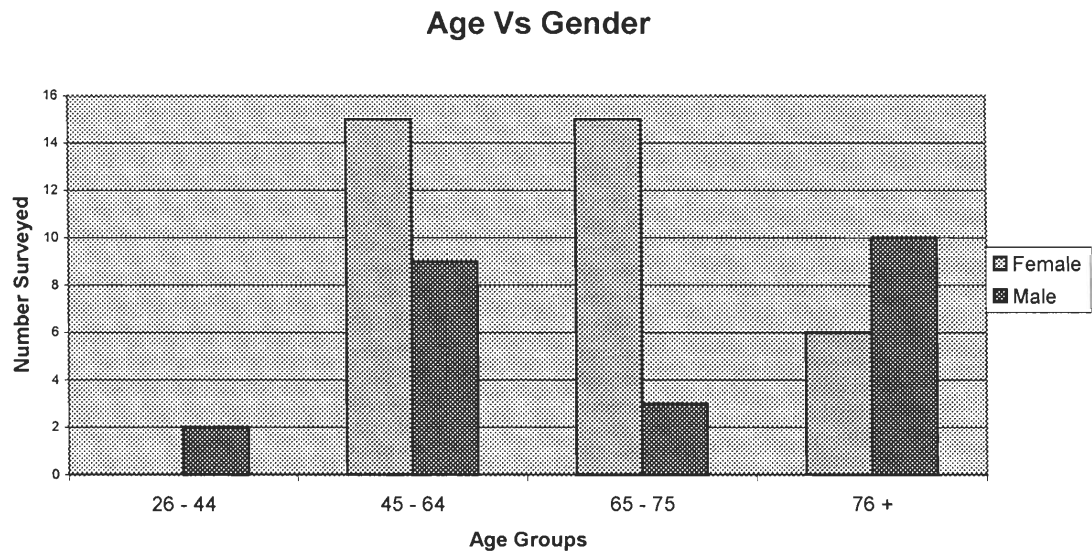


Figure 4-3 Gender ratios that we recoded broken down by age group

We were not able to confirm the gender breakdown in the list used for our postal survey. This list was obtained anonymously from Carers Support Merton, and as such, we were able to have the questionnaires sent out, but were unable to view the names of these carers.

Another possible reason for the gender imbalance in our data may have to do with other factors suggested in the book *Working with Carers*, where we read that “the imbalance appears in other categories: there are slightly more unmarried daughters caring for parents than sons, but significantly more married daughters” (1998, p.30) As we did not ask any questions pertaining to the carer’s relationship with the cared-for, we were not able to confirm how much of an effect this relational aspect of caring may have influenced our data.

4.6.2 Carers Age versus Employment

The job of providing care for another individual is a financial responsibility in its own way. The use of the word job in this case is intentional, as it brings to mind the topic of employment. The key difference separating a professional from a carer (or informal carer as they are sometimes called) is that carers are not paid for the services they provide. This does not, however, mean that the carer will not incur many of the same expenses, as a care professional would charge a user for. These expenses include everything from medication and linen cleaning to washing and hygiene duties. All of these services take time to perform and the more services that are required, the less time there is to do the other essential daily tasks.

The job a carer performs can easily be compared to a regular job given the number of tasks that must be completed and the time frame for their completion. Tasks such as administering medication must be performed on a regular basis and, if the cared-for cannot be left alone for an extended period of time, the carer effectively takes on all the responsibilities of a full-time nurse. When asked how many hours of care our interviewees provided in a week, an overwhelming majority reported that they cared for more than forty hours, or the equivalent of a full week's paid labour. This was true for members of all three age ranges we recorded. In addition, some carers find it necessary to also work a regular job in order to meet the costs of providing care.

When we analysed our telephonic survey results, we found that most of the carers who reported working either part-time or full-time were below the age of sixty-five. However, there was one carer over this age who reported working part-time. Some carers chose to continue work mainly to supplement their pension income; however, others use

work as an opportunity to fill the gap created by the passing of the cared-for. This use of part-time work to replace the time spent caring for another is evidence to the argument that caring is perceived as a job, that it does carry a sense of accomplishment that appeals to some carers. Another interpretation is that the added task of working helps to alleviate the isolation that many carers suffer from while looking after another.

The two graphs shown below indicate the similarity between the job of caring and regular employment. The graphs indicate that most carers do not work because they provide full-time care. Of those that reported less than forty hours of care given a week, the carer's location relative to the cared-for was the most frequent reason given for the limited care.

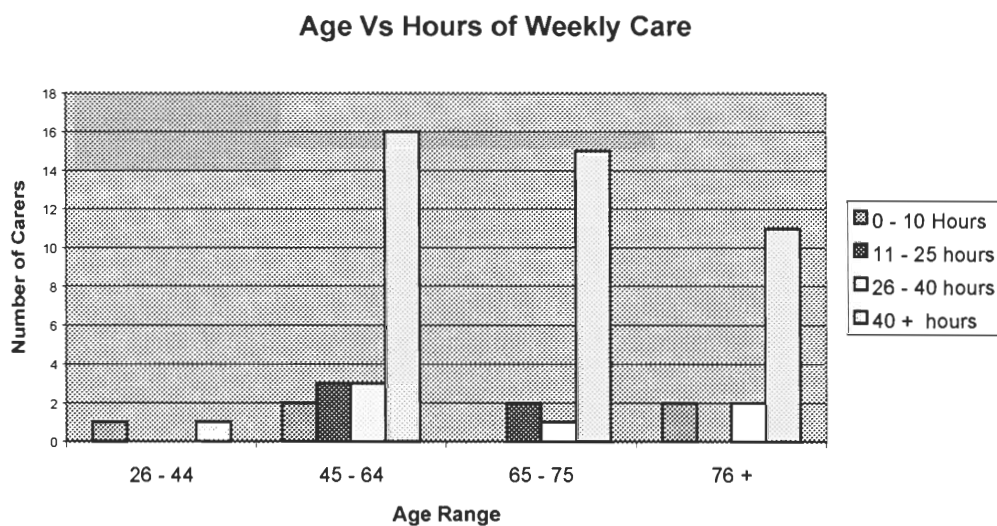


Figure 4-4 Hours of care provided by carers in each age range.

Age Vs Employment

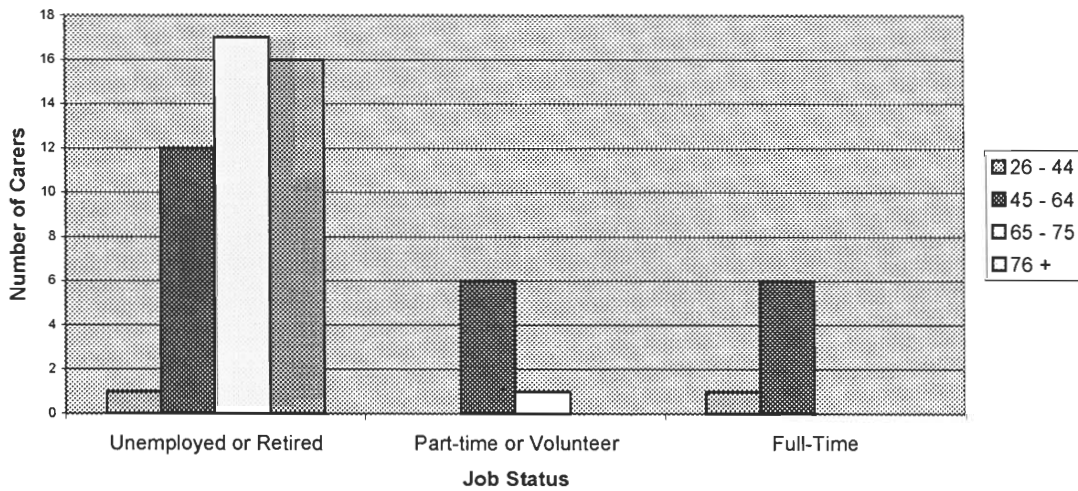


Figure 4-5 Employment status of the surveyed carers.

One possible reason suggested for why so many carers do not work regular jobs is that their role as a carer has such a significant impact on their lives that they can rarely find an employer willing to provide hours with enough flexibility to allow them to do both jobs (Working with Carers p.47). One carer we read about gave this testimonial for how care giving limited his ability to continue work:

“I gave up working in my forties to care for my wife... I know I did the right thing, but some times I look at her and think about all the things I gave up to care for someone who does not even recognise me anymore.” (Working with Carers p.47)

Such statements emphasise the strain caring places on people’s lives, not just in the added responsibilities but also in terms of sacrifices that must be made in other areas of life.

Putting monetary sacrifices aside, other important issues such as family and friends who

are never seen and the freedom to travel or spend leisure time pursuing hobbies can all be dramatically cut short.

Judging from the results of these interviews, it is clear that some sort of attention must be given to the physical and financial ability of a carer to continue conducting their caring role. Though many carers report frustration and periods of doubt as to whether they can continue, few are eager to break from the equivalent of a working full-time job even when they are well beyond the age of retirement. Many consider caring to be their responsibility and not one that is easily passed onto someone else. They also may find some reward in the knowledge that they are helping someone for whom they care. For an assessment to properly evaluate all the needs of an individual, it must be able to consider the time contribution and sacrifices made by that person. The goal is to recognise the scale of the job being performed and to offer assistance and services comparable to those given to someone who is paid. Such services focused on are breaks, and the flexibility to use the breaks as the carer sees fit. Just as a paid employee is given vacation time and leave for illnesses, so too should a carer be allowed to take time off to focus on his or her own needs from time to time.

Special consideration must also be given to those who must continue working to support other family members or to continue meeting other expenses. These people need to have day centres and sitting services available for the times they are not able to be with the cared-for. This is a particularly common problem among carers between the ages of 45 and 65 in our study; it is also a problem for young carers who were outside the scope of our research. Older people can often claim pension benefits to help cover expenses,

but someone who had given up work before reaching this point may find themselves in a more difficult financial situation.

4.6.3 Carers Age versus Health

When speaking to carers on the phone, we often found that as the carers themselves tend to be older people, the physical condition of the cared-for is not the only concern. The health of the carer was frequently mentioned as some sort of limiting factor in terms of the level and type of care they could provide. These issues range in type and severity from issues like stress and depression, to long term concerns such as arthritis and various serious medical conditions.

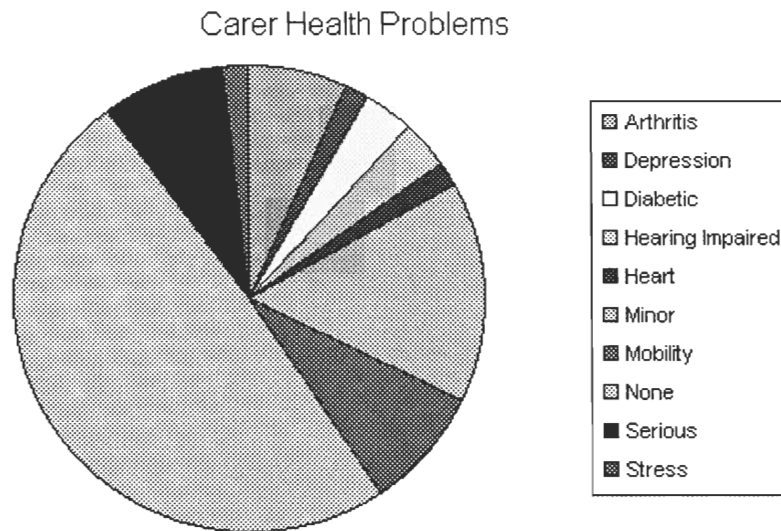


Figure 4-6 Health problems reported in telephonic interviews. This chart does not represent the entire range of medical concerns, but for our purposes it clearly indicates the need for taking the carer's health to be taken into account when performing a needs assessment.

Though we expected to find many carers, especially the elderly, having moderate to serious health concerns of their own, the specific types of issues and the fact that many carers reported multiple concerns sometimes raised the question as to who was caring for

whom. This was more often the case when both the carer and the cared-for were elderly individuals. Our data showed an increase in reports of serious health issues in the 75+ age range as well as the fewest number of individuals reporting no medical concerns in this same range. A bit surprisingly the greatest number of reportedly healthy carers appeared in the 65-75 age range. As the youngest group of carers we spoke with, our initial hypotheses was that they would be the healthiest. This seems to indicate that poor health does not necessarily come about because of old age – caregiving may also have a place.

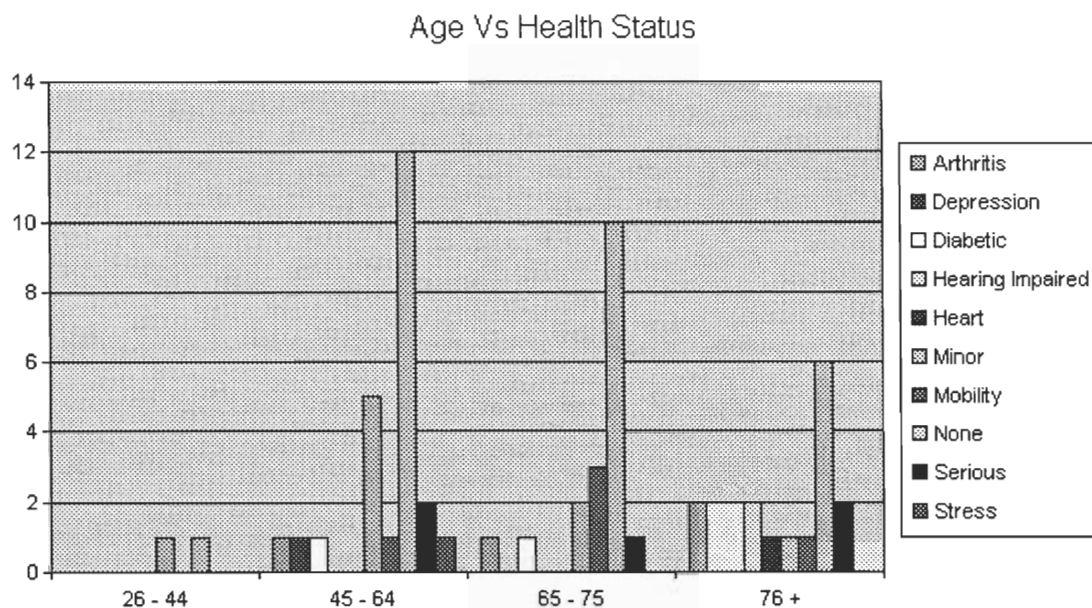


Figure 4-7 Approximate ages of which a number of specific health issues have been reported. For simplicity, some health categories such as ‘Serious’ have been generalized to cover a broader range of specific issues.

Due to our limited data pool, we compared our results on the reported health of carers with those of a number of General House Survey results. One survey, performed in 1985, showed 50% of carers over the age of sixty-five reported some sort of chronic illness (Working with Carers p. 46). Whilst we did not specifically look for chronic

illnesses, issues such as high blood pressure and arthritis would fall under this category. With half of our twenty-six carers over the age of sixty-five reporting some sort of illness, chronic or other wise, the results of this survey appear to closely reflect the same finding we encountered a full sixteen years later. Additional information in the GHS also reported that of the carers aged over forty-five who contribute twenty care hours or more a week, 37% had suffered a debilitating illness in the past year (Working with Carers p.46).

While such findings can support our hypotheses that caring can lead to health problems, there are other possible explanations for the correlation between caring and poor health. A second analysis of the GHS done by Parker and Lawton (1994) suggests that “the majority of carers reporting they had health problems are older people and women who, statistically, already have poorer health” (Working with Carers p.46). This interpretation assumes the carer had a pre-existing state of poor health and while this is a completely valid possibility, it is not one that is held in common by most carers. In fact, when asked by the Carers National Association (CNA) if they believed their health had suffered due to their caring role, 60% of carers reported they did believe their health had suffered (Working with Carers p.47).

Despite either of these opinions towards caregiving and health problems, there has been little sign that these problems have caused carers to abandon their caring roles. We did find that a majority of carers providing more than forty hours of weekly care were healthy themselves, but this does not pay justice to the high number of carers we spoke to who had health problems and provided the same amount of care as the healthy. In fact, more carers with health issues provided full-time care (forty hours a week or more) than

those with health problems who provided fewer hours per week. One carer in particular told us that because her husband was a difficult person to deal with, she did not feel it was fair to ask a nurse or other care professional for assistance of any kind. She took care of him for almost eight years in her home, performing all the household chores, bathing and other hygienic tasks for her husband until finally she was told by a social worker that she had to place him in a long term care facility. This illustrates the significantly high level of responsibility many carers have and their willingness to cope with circumstances others would find difficult to imagine.

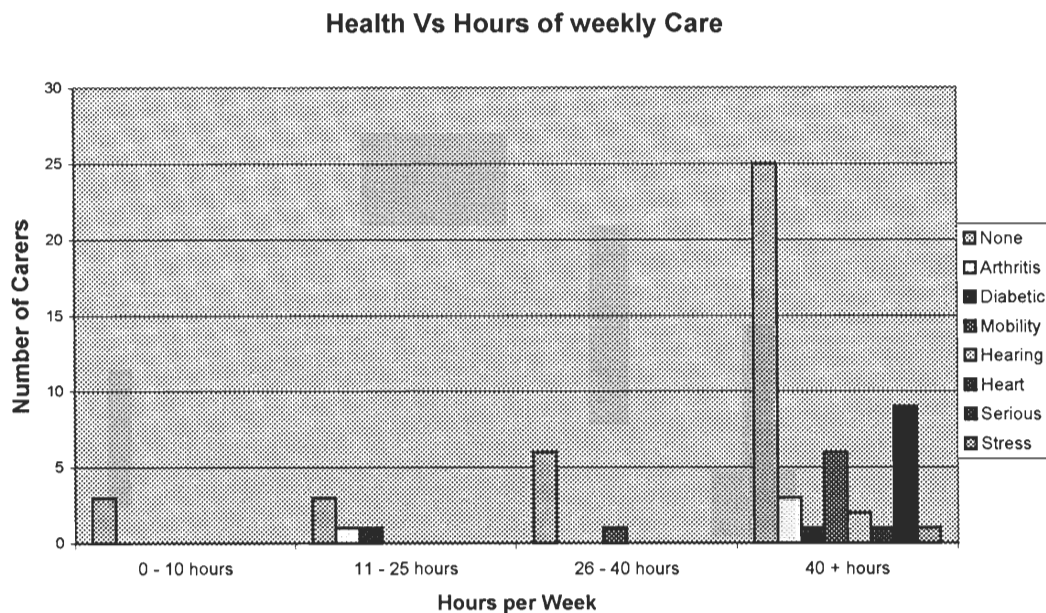


Figure 4-8 Hours of weekly care provided by carers with a number of different health problems. With the carer’s age not a factor, note the concentration of carers with health problems continuing to provide 40+ hours of weekly care.

By examining the situation closely from the carer’s perspective, we found there were a number of specific problems that carers reported most often. These problems included issues such as depression, back troubles, sleep deprivation, and exhaustion,

which do not always get coded as actual health problems (Working with Carers p.47). A number of the carers who responded to the telephonic interviews also reported similar issues, often as a side comment. This further emphasises the problem that some issues known to lead to breakdowns and other serious forms of mental stress are often overlooked by those who suffer from them and not just the health providers.

The issue of carer depression has been gaining more publicity in recent years and a number of carer advocacy groups focus their attention on this subject. Currently, there is no specific provision made for the treatment of this condition other than to see medical professionals. With the number of carers who reported battling depression in our interviews, it may be necessary for the Borough to consider other methods for possibly preventing depression rather than just treating the condition as the need arises. As previously indicated in other sections, social isolation has been linked by many as a significant contribution to depression amongst carers. It has been reported that “caring can cause a deep sense of social isolation, especially for single carers, who may have used up all of their respite time to work and thus have little opportunity to meet with friends” (Working with Carers, p.49).

Of the carers we spoke with who reported bouts of depression, many did not take any action to help cope with the issue. Others reported that the depression set in sometime after the passing of the cared-for. By this point in their lives, they had become so wrapped up in the daily activities of caring, they did not know how to re-enter social situations and indicated a feeling of uselessness. Many of them may have been served better, by more frequent evaluations from a social worker or from available from counselling services provided to carers and former carers alike. This indicates the

importance of mental health as a dimension of the assessment that may need greater emphasis.

4.7 Carers' Requests for Social Services

One of the most useful aspects of our telephonic interviews was the opportunity we gave carers to make their own recommendations to Social Services as to any types of assistance they would like to see offered. Though not every carer knew how to answer this question, there were others who seemed as though they had been waiting for such an opportunity to provide feedback. In particular, those that work or had previously worked as volunteers were best able to help us in this matter.

The primary concern that most carers mentioned was the lack of personal contact with the social worker. Some carers felt that their social worker had not done enough to explain all the details of the assessment form they filled out. Many carers believed social workers had not made frequent enough attempts to check up on the state of the carer and the cared-for. Given that Social Services deals with a relatively large number of clients, it is not surprising that carers would mention some lack of personal contact. Many cited examples of how they had sought better attention from volunteer organisations or private care facilities. This is an understandable situation, but that is not to say that social workers should not be encouraged to improve their personal interaction with clients. On a positive note, there were carers who were extremely satisfied with the level of help they received from their social worker and appreciated the patience they were shown when they did not understand what was being explained to them.

This issue of infrequent contact with social workers occurred most often when the carer did not live with the individual they were caring for. This meant that the carer may

not have been around at the time the social worker made a visit to the home of the cared-for. In some cases, the social worker would not have even met the carer until well after the cared-for had been utilising Social Service assistance. For this reason, it is now evident that more effort must be made to identify and maintain contact with the carer once Social Services begins to develop a “Care Plan” for the cared-for. A number of carers stressed the need for such changes, after informing us that the cared-for individuals they looked after had passed away some time ago and no update had yet been made to the database – they were still listed as a carer.

Other suggestions put forth by the carers we contacted included making provisions for less costly services. We were told by a number of carers that they had specifically declined some specific service that the Borough offered them because it was more cost effective for them to find a similar service provided by a private company. It was even suggested that Merton might be able to save on the cost of services if the carer was provided funding to seek their own outside services. If this were not possible, then the preferred alternative was to have Social Services provide services in a similar fashion as the voluntary sector. This approach is based on consistent aid, where the same individual is sent to a home to provide whatever service is needed, rather than to have the services performed by a number of different people.

4.8 Communication Conflicts with Social Services

From our surveys, we discovered some conflicts that have risen between Social Services and the carer. One of the biggest problems between the two is the lack of communication on both ends. Since 1995, all social workers were required to provide a carer’s assessment to all carers that requested one – if, and only if, the carer requested on

when the cared-for was being assessed. In 2000, the new Carer's and Disabled Children Act (C&DC) created more legislation that was meant to provide carers the opportunity to receive an assessment in their own right. Despite this legislative refinement of the Carers (Recognition & Services) Act of 1995 many carers still were not aware there was a carer's assessment at all. After analysing our data, we found that 44% of carers had no knowledge of the carer's assessment prior to our contact.

This lack of awareness points to a breakdown in communication among all care provision agencies and between carers and Social Services. The Local Authority in Merton has had the responsibility to provide these carer assessments since the C&DC Act was passed in 2000. Since then, a formal guideline for the delivery of such assessments was not available to social workers until November of 2001. In this time, the Borough Council and the other care organisations funded by Social Services have shared the job of informing carers that assessments were available. With less than half of all contacted carers reporting that they had been informed it is evident that more aggressive efforts must be taken in order to properly serve the carers' needs. Such efforts would include better communication and cooperation between all parties: carers, social workers, volunteer and charitable organisations.

Another source of conflict that accompanies the carer's assessment is the sensitivity issue with respect to the wishes of the cared-for. Many of the carers we spoke to over the telephone were confused by the question of what types of services they would like to be provided. So much of the carer's energy is focused on the needs of the cared-for that they often responded to this question by listing services that would actually be provided to the cared-for. Since the aim of the carer's assessment is to assist the carer's

needs, some skill must be utilised to evaluate what the carer needs to improve the quality of their own life. These services would be separate from those given to the cared-for. The problem encountered here is that the issue of separate services may be viewed negatively by the cared-for as selfish or unfair behaviour on the part of the carer.

Conflicts of interest between the needs of the carer and the wishes of the cared-for must be handled delicately by the social worker. This may mean asking the carer if he or she wants the cared-for to be present when an assessment is requested. This would be one method of preventing conflicts that could arise if the carer requests services that the cared-for does not want (Working with Carers p.69). In order to make the option of separate assessments available, carers must be periodically reminded, via post, that they can request such a session, since the mention of such a provision in the presence of the cared-for maybe cause for suspicion.

There were a number of carers who reported having particular difficulty communicating with their social worker even when they were aware of the services being offered. We heard numerous accounts from carers who were seeking an assessment of their own but lacked the knowledge of who to contact. Most of these carers reported that they had heard something about the carer's assessment either from an outside care provider such as an in-home nurse or from a past mailing that they had lost track of. This could indicate that the carers themselves may be hesitant to contact a social worker or it may point out the need for more aggressive promotion of the assessments, especially since the process is relatively new.

Another communication shortcoming that carers mentioned was the infrequency of social worker contact. Some carers who do not live with the person they care for

reported not speaking to their social worker for an extended period of time, in one case as much as three years. This occurs mainly in cases where the cared-for lives independently and relies on periodic weekly visits by the carer.

There were quite a few people who declined having an assessment done. These people often felt it was their job, or responsibility to the cared-for, to provide as much assistance as possible. Others did not see the reason to have their own needs assessed as they believed the cared-for deserved all the attention. This is due to the fact that quite often the cared-for is an ill spouse or parent or other relative whom they do not want to lose. Carers often have fears that if Social Services were to become involved, they might lose their loved one to a long term care facility, or they may be found unfit to continue providing assistance. These people would also prefer not to inform Social Services about whatever income and/or savings they might be able to pay for some of the services they might seek. Therefore, they reject a carer's assessment and attempt to survive with the resources they already have.

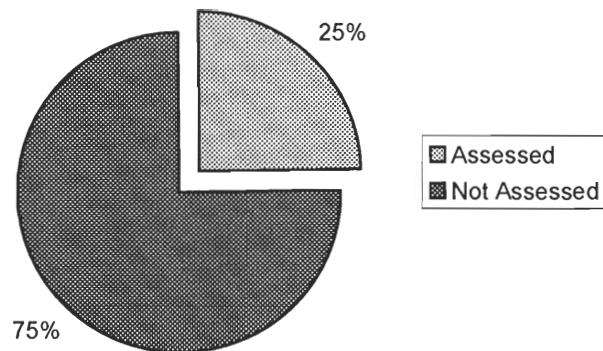


Figure 4-9 Percentage of carers who had previously been assessed.

Many of the people who we have spoken with have maintained a common response: they would like Social Services to better inform them about the new assessment procedure and what would be available to them after completing it. They would like to be able to find out through telephone calls, mail-out pamphlets, and personal contact from social workers, the advantages of filling out an assessment. They would like to be able to see if an assessment could be financially advantageous to them.

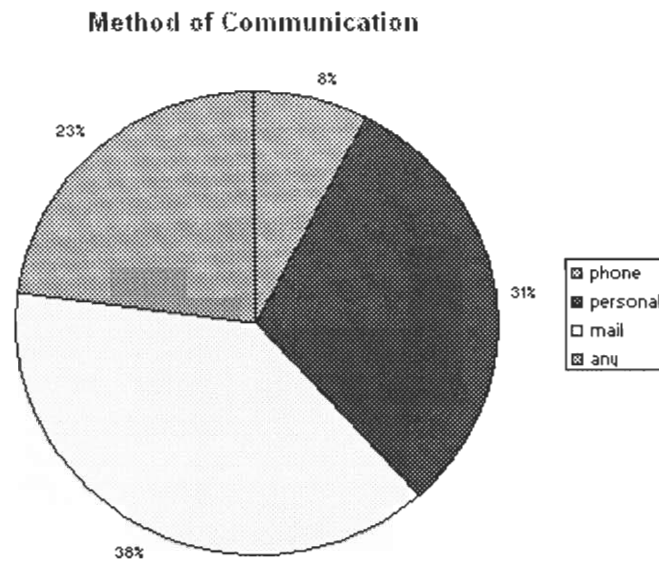


Figure 4-10 Preferred methods of Social Service communication for carer assessment

4.9 Cross Borough Problems

A common problem that turns up quite frequently in Merton and in other boroughs is the problem with cross-borough responsibility. In the event that the carer lives in another borough from the cared-for, concerns surrounding the responsible borough crop up. The borough the cared-for lives in does not want to provide assistance to anyone from another borough that in theory should be capable of seeking assistance from their own borough. However, the carer wouldn't be providing assistance at all if the cared-for individual didn't need the help. These people often fall through the cracks in the interpretation and there is nothing that can be done for them.

This problem is not only seen with Social Services; many voluntary organisations, including Merton Crossroads, will only provide assistance to carers from Merton. Therefore, there are very few places that the carer can seek help, or even a break from their caring role.

Steps were recently taken to prevent further, reoccurring problems of this nature. A Draft Cross-Borough Protocol was acquired from our liaison for the Boroughs of: Camden, Croydon, Kingston and Haringey. These boroughs have proposed that in the future, the borough of the cared-for should be responsible for the carer's needs, and that this borough should purchase the services from a provider in the carer's borough. These steps should help prevent further instances of cross-borough concerns in the future.

4.10 Social Worker Interviews

Our group interviewed social workers from the Gifford House who have had significant experience dealing with the carers of older people, to gauge the role of the assessment process as viewed by the various parties involved. The primary goal of this exchange was to analyse the carer's assessment process. We wanted to find the parts in the assessment process that were working well and those that were lacking. This was in an effort to find ways to improve dialogue between the social worker and the carer, and therefore, to develop better methods of understanding the needs of the carer.

One of the most important issues that concerned social workers during our interview with them was their level of training. Many felt they were ill-prepared to deal with and understand the new legislation and said that the guidelines book provided was too wordy and didn't touch on the intricacies of the new legislation. They also indicated that they were having a hard time determining what they could provide for a carer and what resources were available for them to use. As the group stated, the reason for this was because they knew there was money available to them to use through the Carer's Support Grant, but none of them could give an example of when the Grant could be applied.

In regards to the assessment process, the social workers recognised many of the elements that they felt were difficult to deal with, those that needed to be changed, or those that had to be refocused. Another reason carers chose not to be assessed, they told us, was because carers mistook the term 'assessment' to mean 'finances' and many are not interested in services they have to pay for.

Initially, a discussion of how social workers perform assessments is necessary so one can acquire a good impression of the entire process. Each of the social workers that we talked to had their own pre-developed way to perform an assessment. Some felt that leaving the assessment with the carer would produce better results, because the carer would have time to think about the questions and fill them out in detail. But others argued that, in their experience, it led some carers to misunderstand questions and to provide meaningless answers. When this issue was raised, we debated whether the cared-for should be present while the carer was getting assessed. A majority felt that the assessment should be performed with only the carer present, but some interjected that the presence of the cared-for sometimes helped the carer answer questions. From these findings, one can see that the way an assessment is given varies widely with the environment that the carer is in and the social worker giving the assessment.

The social workers were also concerned about the way the questions in the assessment were worded. By the end of the discussion, most felt that the assessment should be refocused in a more positive manner, because currently, it seemed like the form was pointing out shortcomings in the way the carer was performing. Many felt that the assessment should gear itself towards helping the carer recognise all the work they do, and what they feel they need help with. In conclusion, the social workers felt that they

needed more – in terms of resources, training, and the assessment form itself, in order to effectively analyse the needs of the carer.

5 Conclusions and Recommendations

5.1 Introduction

During the closing stages of our project, we present our conclusions and provide recommendations to LB Merton about the carer assessment process and the services being provided to carers. By analysing our results, we were able to draw conclusions about how carers feel about the assessment process and the services they receive from Social Services. Using our analysis, we were able to formulate recommendations, which point out ways in which LB Merton Social Services might improve carers' response to and perception of the assessment process.

5.2 Profile of Carers in Merton

Using the data gathered with the questionnaire and the telephonic survey, we have drawn conclusions about our sample population. We found that many carers lived with the person they care for, but carers who had other living arrangements usually travelled more than three times a week to see the person for whom they were caring. Although nearly all respondents thought of themselves as carers, most were not aware that they were entitled to be assessed, either individually or when the person they care for received an assessment.

5.2.1 Carer Anxiety

We concluded that carers often hesitated to seek assistance from Social Services for a variety of reasons. Some carers were not comfortable with sharing personal details with a public agency, such as Social Services. Other carers felt that if they sought

assistance, they could lose control over the person for whom they are caring. Many carers felt that it was their own responsibility to look after the cared-for, even if it meant fewer hours at work, lack of sleep, and no free time. One of the persons interviewed via telephone stated, “I don’t want to leave my husband at any time.” Many other carers felt the same, and indicated that they did not want a vacation for fear of being away from the cared-for. Some used intrusion as an example for refusing services, saying, “[I do not want] other people coming into my house” and “[They] would only get in the way.” Some hinted at the uselessness of the respite service, stating that there was no need for them to leave the person they were caring for at any time.

5.2.2 Multiple-Borough Difficulties

We also conclude that the lack of knowledge does not necessarily centre on the assessment itself. One person felt that Social Services would not be able to provide assistance of any sort because they lived in one borough, while the person they were caring for lived in another. However, our understanding is that the Cross-Borough Protocol provides for situations such as these, where carers look after someone living in a different local authority.

In order to meet the requirements for this program, the Cross-Borough Protocol provides guidance regarding the various areas of caring. It assigns a “responsible local authority” that is accountable for completing the assessment and any subsequent commissioning of support services. It also monitors the costs of services provided and decides which party (carer, local council, or other borough) is liable for such expenses.

5.3 *Services for Carers*

There are a variety of services available to the carers in the borough; some are well received, while others are not. Usually, this has to do with the financial implications of the service and the efficiency with which it is provided.

5.3.1 Service Recommendations from Carers

Through our telephone survey and questionnaire, we have received numerous comments regarding the types of services carers would like to see offered. Among these, in-home services such as cooking, washing and bathing were the most frequently requested. Those that receive food through the Meals-On-Wheels program see it as a worthwhile service, whether they pay for it or not, but concerns were raised by some individuals who stated that their meals were not delivered on time. Meals-On-Wheels is an important program offered by Social Services and, if possible, should be improved with new food plans. A frozen meal plan has recently been introduced, where the cared-for would receive up to three days of frozen meals in advance, so they would be able to eat at a time that is convenient and not when their food was delivered. One possible addition to the Meals-On-Wheels program could be a weekly frozen food plan, where the cared-for would get a week's supply of frozen meals. For example, if the carer worked during lunch, the cared-for would be able to prepare their meal on their own.

5.3.2 Informal Services

Many carers requested informal services, which are not necessarily provided by any single organisation. One idea was to provide a personal alarm that could be used to call for help by people in the carer's residence or by the person being cared for. Another

suggestion was that social workers make occasional telephone calls to the cared-for person's home to check up on their general well being.

5.3.3 Voluntary Organisation Involvement

We learned from our interviews with voluntary organisations that, in some cases, services offered by these organisations were preferred over those offered by Social Services mainly because of a quicker service response rate. The voluntary sector uses a different approach to assessing the carer in his or her own right. The assessments these organisations perform are different because they are informal, making them more comfortable for the carer. Often voluntary agencies, such as Carer Support Merton and Crossroads, will ring the carer at home to ask them a series of questions concerning their needs and situations. This examines the carer's environment and struggles they encounter while caring so that the agency can provide proper services to these individuals. It is important to note that through these assessments, there is no investigation into the carer's finances, which often puts them more at ease. Understanding how voluntary organisations performed their assessment was important in backing our results to the questionnaire and in explaining why some people in the borough turn directly to the voluntary sector instead of using Social Services.

Through our interaction with voluntary organisations, we have seen that many of the people who receive the services offered to them are pleased with the extent of service they receive. Carers see voluntary organisations as alternative channels of assistance and use them when they feel Social Services will not be able to help them or provide them with an adequate amount of support. Social Services should continue to work in conjunction with voluntary organisations and should recommend new carers to these

establishments as well, as both Social Services and voluntary organisations can work together to meet the needs of carers.

5.4 Carer Assessment Process

The revised assessment procedure has not yet been well recognised by carers in LB Merton. These carers are not aware that they are eligible to receive an assessment from Social Services. A few carers, after being briefed on the assessment process, indicated that they felt it was the responsibility of social workers to make them aware of such provisions. Some suggested that social workers should telephone them in order to keep them informed of recent changes in legislation and of new services available.

5.4.1 Introduction of Dedicated Assessment Staff

In some cases, Social Services may not be the best organisation to perform assessments of carers. Social workers are usually trained to work with all types of people and to provide assessments for all types of carers. Sometimes, however, this general understanding of the population may not be the best method for analysing carers' needs, even though a standardised assessment form is used. Some organisations perform assessments with a dedicated agent, whose primary purpose is to thoroughly examine the needs of carers. This idea would prove to be extremely useful for Social Services and will allow them to establish seamless continuity when analysing the carers' needs. The dedicated agent would not have to be a social worker, thereby providing an impartial view from which to perform an assessment.

5.4.2 Social Services and its Public Visibility

Among the suggestions that we are able to provide, those that concentrate on Social Services and its visibility to the public are first and foremost. Many carers have suggested that the best way for them to be informed about changes in policy or provisions is to be notified by Social Services. Information can be passed from Social Services to carers by word-of-mouth, newsletter, post, or social worker; all are viable methods of knowledge dispersion. Although it is not always possible for social service workers to contact carers via telephone each time changes in policy or services are made, a word-of-mouth approach is very feasible. Many carers have meetings, seminars and other social events that they attend frequently – and these provide an effective outlet for the distribution of data. Although this bears the risk of false interpretation of information by carers, it is an unavoidable drawback that comes with this medium. A more indirect approach, albeit a more practicable one, might be to spread information via newsletter or other form of post. The use of a newsletter guarantees that the information reaches carers directly, accurately, and quickly.

5.4.3 Comments on the Assessment

Based on interviews with carers who had already been assessed, we noted that a majority felt the process was relatively straightforward. However, many carers had not had the opportunity to look into the results of their assessment – and others did not realise that they were able to obtain copies of these results. Nearly all carers, whether or not they had been assessed, agreed that their needs should be assessed frequently, or more specifically, when their circumstances changed significantly. Since the carer's

assessment plan already provides for the latter case, Social Services has well anticipated this need.

5.5 Room for Improvements

During the course of our research, we encountered a variety of shortcomings and limitations that affects the way in which social workers perform their job. To this end, we developed a small group of informal recommendations which we wish to summarize in this section.

5.5.1 Network of carers

It would prove useful for Social Services to develop a list of carers who would be willing to share information with the Borough whenever feedback opportunities existed. Carers would be able to provide their views through media such as online surveys, mail-out questionnaires, focus groups, and informal telephone conversations. This type of group provides a constant source of direct information whenever Social Services needs it. This could also be linked with a dedicated carer's website, where carers would be able to enlist themselves with such a feedback group. The website could also guarantee that carers will be able to voluntarily remove themselves from the list at any time.

5.5.2 Development of website

The UK government has already made a push towards moving all publicly available information to electronic form. Many other boroughs have taken steps to ensure that all information available within their bounds is also freely shared online. LB Merton has also recently been taking such measures to ensure that it too share information online. Currently, a small section of the Merton website (<http://www.merton.gov.uk>) holds

information specifically for caregivers in the borough. To improve this part of the website, we can make the following suggestions:

- The site should provide clear, easy-to-understand definitions of all the terminology involved in the caregiving and assessment process ('carer', 'assessment'). The goal of this part is to clear any doubts about what the borough provides, and to make sure that carers are not confusing the carer assessment process with the financial assessment.
- The development of an online carer's discussion board would be useful in that it would allow carers to discuss issues and disperse information freely to all others who access the site. This online discussion also has an added bonus in that it allows the Borough to look into the issues currently surrounding carers.
- The utilisation of a 'website feedback' section on the website will allow carers to provide immediate comments as to the nature and content of the site. These responses would allow the Borough to develop a more wholesome portal for the exchange of information.

5.5.3 "Care Plan" for carers

Currently, once the cared-for has been assessed by a social worker, they are provided with a "Care Plan". This plan outlines the services that will be provided to meet the needs of the person being cared-for. Conversely, there is no such plan in place for carers in their own right. Once a carer's assessment has been performed and Social Services is aware of the carer's needs, steps are taken to provide services to meet them. There is nothing in existence, in terms of a "Care Plan" that a cared-for person has, to provide for the allocation of services and the ability to review the services being provided

to a carer. The development of such a plan will provide the Borough with a standardised means of keeping track of each carer, the services provided, and the budget set aside for meeting their needs.

5.5.4 Improvements with SOSCIS

We are aware that there is a new system in development that will be replacing the SOSCIS database, and in respect to this new database we would like to propose some ideas. Ideally, it would be beneficial if the new database were graphically represented; SOSCIS is currently all text-based and involves primitive navigation through numerous screens. The new database should be able to easily provide for a link between all the people involved (the cared-for, the carer, the next-of-kin, and the social worker). It should also provide easy navigability so that the user does not have to be burdened with typing in codes for each screen needed. The text input areas in the system should also be reorganised so that it is trouble-free for the social worker or other staff member to enter all pertinent information, especially when they are performing another task simultaneously, such as answering the phone or talking to a carer.

Appendix A - Carers Mail-Out Cover Letter

Friday, 1 February 2002

To Whom It May Concern:

Allow us to introduce ourselves: we are a small research team working in conjunction with the Merton Social Services Department to conduct an analysis into the assessment process that is currently used within the borough. The team is made up of four undergraduate students from the Worcester Polytechnic Institute in Worcester, Massachusetts USA and is managed by Colin Willard from the Housing and Social Services Department.

Through the use of this questionnaire, we will be seeking to learn about the success of the carer assessment process and the relationship that Merton Social Services maintains with carers after the assessments have been carried out. The data gathered will be anonymous and will be collated with the results from other carers before being analysed. At the end of the project, copies of anonymous data sets will be given to the team members for their own research purposes.

We encourage you to be open about your responses (even if you were hesitant during your previous meetings with social workers). You do not have to participate in the survey but we strongly recommend that you do. We greatly value your views on the services offered to you. If you have any questions, please contact Colin Willard at 0208 545 4002. We thank you in advance for your cooperation.

Yours faithfully,

WPI Research Team

Appendix B - Carers Mail-Out Questionnaire

Carer Assessment Evaluation Questionnaire London Borough of Merton Housing and Social Services Department

Instructions

This section outlines instructions for completing this questionnaire. Please read this section carefully before attempting to proceed to the survey itself.

This is a survey that is attempting to study the relationship between Social Services and carers with regards to the newly revised carer's assessment process. A carer is an individual who looks after a friend or relative who needs support because of age, physical or learning disability or illness, including mental illness. A carer is not an individual who is a paid care worker. The carer's assessment is a process through which Social Services can learn about the support that individual carers need to enable them to continue in their caring role. The process starts when a carer is referred, or requests an assessment, or is offered an assessment when the person they care for is being assessed. It is in a standardised format so the carers can complete it themselves or through a social worker.

Completing the Questionnaire:

When faced with a multiple choice question, such as a yes-or-no questions, simply tick one or more of the pertaining choices (depending on what the question itself is asking for), like so:

1. Are you a carer?	<input checked="" type="checkbox"/> YES	<input type="checkbox"/> NO
2. What method of public transportation do you use on a regular basis?		
	<input type="checkbox"/> Taxi	
	<input checked="" type="checkbox"/> Bus	
	<input checked="" type="checkbox"/> Underground	

Some questions ask that you provide fill-in answers. When approached with such a question, please provide a brief, but useful response, so that we can best interpret your feelings.

1. Are you a carer?
Yes, I believe I am a carer. I understand that I have certain rights as a carer, which has been made clear by provisions given in November of 2001.
2. What method of public transportation do you use on a regular basis?
<u>I make use of the bus and the Underground at least twice a week.</u>

After you have familiarised yourself with the types of questions and answers on this survey, you can start the survey by turning to the next page.

Part 1: About Yourself

1. What is your gender?
 - Male
 - Female

2. What age group do you fit into?
 - 16-25
 - 26-44
 - 45-64
 - 65-75
 - 76+

3. Do you live with the person you care for?
 - Yes
 - No, I travel _____ times a week to see them.

4. How many hours a week do you spend caring?
 - 0-10 hours.
 - 11-25 hours.
 - 26-40 hours.
 - 40+ hours.

5. Are you currently employed?
 - Full-time
 - Part-time
 - Volunteer
 - Unemployed
 - Unspecified

6. Are you suffering from any significant health problems?
 - Serious illness
 - Mobility problems
 - Visual impairment
 - Deaf or hearing impairment
 - Difficulties with communication (without speech, literacy, etc)
 - Other _____

7. In your experience, how easy or difficult has it been to contact Merton Social Services?
 - Extremely difficult
 - Somewhat difficult
 - Not difficult at all

8. By which method were you most successful?
 - Telephone

- Email
- In person
- Post

9. What type of assistance /service, if any, would improve your daily quality of life and help you to continue in your caring role?

10. Are you aware that you as a carer are entitled to an assessment when the person you are caring for receives one?

- Yes
- No

11. Are you aware that you as a carer are entitled to an assessment in your own right (even if the person you are caring for is not being assessed)?

- Yes
- No

12. What is your current status regarding the assessment process?

- I have been assessed already. Proceed to part 2.
- I have not yet been assessed. Proceed to part 3.

Part 2: Already assessed

13. How was it determined that you are a carer?

- Social worker
- Brochure/Other Mailing by Social Services
- Self-designated

14. As a carer, do you feel that you were provided with enough information to understand the assessment process?

- Yes
- No

15. Did you feel that you were involved with the assessment process and the decisions that affect you?

- Yes
- No

16. If you answered 'no' in question #15 what did you feel was keeping you from being involved?

17. How straightforward do you feel the assessment process was?

- Very complicated
- Somewhat complicated
- I experienced no difficulty at all.

18. Have you seen a copy of the assessment results of the person you are caring for?

- Yes
- No

19. Have you seen a copy of your assessment results?

- Yes. Proceed to question (20).
- No. Proceed to question (21).

20. Do you feel that the results of the assessment accurately described your needs?

- Yes
- No

21. How effective has Social Services been in meeting your needs?

- Not effective
- Somewhat effective
- Effective
- Extremely effective

22. Have the services provided to you as a carer met your expectations?

- Yes
- No

23. How frequently do you feel your needs should be assessed?

You have completed this questionnaire. Do not proceed to another section.

Part 3: Not Assessed

24. Do you think of yourself as a carer?

- Yes
- No

25. Which option summarizes why you have not been assessed yet?

- I was not aware that I was entitled to an assessment
- I don't think Social Services will be able to help me
- I use voluntary organisations and that is enough for me

- I am happy with my current situation
- Other _____

26. In question 25, if you ticked the first choice, in what way(s) would you like to see Social Services inform people about what is entitled to them?

27. In question 25, if you ticked the second choice, why do you feel that social services will not be able to help you?

You have completed this questionnaire. Do not proceed to another section.

Appendix C - Carers Telephone Interview Questions

Date: _____ | Time: _____ | Gender: M F

Part 1: About Yourself

1. **How old are you?**
 - (0) 16-25
 - (1) 26-44
 - (2) 45-64
 - (3) 65-75
 - (4) 76+

2. **Do you live with the person you care for?**
 - (0) No. How frequently do you travel to see them at their home?

 - (1) Yes.

3. **Can you estimate the number of hours a week you spend caring?**
 - (0) 0-10 hours.
 - (1) 11-25 hours.
 - (2) 26-40 hours.
 - (3) 40+ hours.

4. **Are you currently employed?**
 - (0) Unemployed (No)
 - (1) Full-time (Yes)
 - (2) Part-time/Volunteer (Some of the time)
 - (3) Unspecified

5. **Do you have any significant health problems?**
 - (0) Serious illness
 - (1) Mobility problems
 - (2) Visual impairment
 - (3) Deaf or hearing impairment
 - (4) Difficulties with communication (without speech, literacy, etc)
 - (5) Other _____

6. **Are you aware that as a carer, you are entitled to an assessment when the person you are caring for receives one?**
 - (0) No
 - (1) Yes

7. **Are you aware that you as a carer are entitled to an assessment in your own right (even if the person you are caring for is not being assessed)?**
 - (0) No
 - (1) Yes

8. **Have you been assessed?**
 - (0) No. Proceed to part 3.
 - (1) Yes. Proceed to part 2.

Part 2: Already assessed

9. How was it determined that you are a carer?

- (0) self
- (1) Social Services
- (2) other _____

10. As a carer, do you feel that you were provided with enough information to understand the assessment process?

11. Did you feel that you were involved with the assessment process and the decisions that affect you?

- (0) No. What did you feel was keeping you from being involved?

- (1) Yes.

12. Have you seen a copy of your assessment results?

- (0) No.
- (1) Yes. Do you feel that the assessment accurately described your needs?
 - i. (0) No
 - ii. (1) Yes

13. Have the services provided to you as a carer met your expectations?

- (0) No. _____
- (1) Yes. _____

14. How frequently do you feel your needs should be assessed/reassessed?

Part 3: Not Assessed

15. Do you think of yourself as a carer?

- (0) No.
- (1) Yes.

16. Is there a reason you have not taken advantage of the carer assessment offered by Social Services?

- (0) I was not aware that I was entitled to an assessment (A)
 - i. In what way(s) would you like to see Social Services inform people about what is entitled to them?

- (1) I don't think Social Services will be able to help me (B)
 - i. Why? / Is there a reason you feel this way?

- (2) I use voluntary organisations and that is enough for me
- (3) I am happy with my current situation
- (4) Other _____

Appendix D - Social Worker Interview Questions

Topic: The Carer's Assessment

1. Do **people come forward knowing** that they have a **right to a carer's assessment**?
 - a. (How high is the **public perception/knowledge about the process**?)
 - b. Do **they understand**, once assessed, **that they have been assessed**?
2. Is Social Services **asking** the **right questions**?
 - a. How difficult is it for **you** to **interpret the meaning of questions**?
 - b. Are they **easy for the carer to understand**?
3. What are the types of needs carers most frequently have?
 - a. Is Social Services capable to meeting carer's needs?
 - b. What services are we best able to provide?
4. How significant is the **presence of the cared-for** when performing the carer's assessment?
 - a. What is the general reaction from carers and cared-for people in terms of the **involvement of Social Services**?
 - b. How **receptive** are **carers** to being **assessed**?
5. Some authorities are **employing dedicated** carers assessment **staff** – is this a good idea?
 - a. What **type of person is best suited** for performing an assessment?
6. What **can Social Services do better**?

Appendix E - Meeting Minutes

Meetings with Social Workers

Merton Carers Assessment Audit

Naveen Selvadurai, Steven Posnack, Brian Jaeger, Patrick Faiola

Interviewee	Gloria Eveleigh
Title (e.g., Head of Community Care)	Planning and Performance Review Officer
Department / Organization	SPPRU – Merton Housing and Social Services
Phone Number / Email	3001
Interviewed by	Naveen / Steve
Date/Time	18 January 2002
Location	Coffee shop
Topic (description)	Assessments

Before meeting:

Care management flowchart (from big white binder):

- First Contact
- Referral
- Community Care Assessment
- Provide Service Care Plan
- Authorisation of Service Care Plan
- Implementation of Service Care Plan
- Monitoring Care Plan
- Review Care Plan
- Closure

NHS Community Care Act 1990

- LAs must do an assessment (community care act)
- if there appears to be a need
- Before act, people had to come forth and ask for assessment; now LAs duty
- Act: take into account, the views of the carer
- a judicial review (Gloucester case) stated that LAs can take local resources into account
- when providing services
- “eligibility criteria” are used to ration services
- only those with highest needs meet these criteria

assessment is carried out

- social worker gets referral from doctor, friend, etc
- worker rings the guy up and finds out whether they want to talk
- sit down with the carer and cared-for and talk with them
- what do they see as their problems
- what services they see as needed
- you are not coming in to take over – don’t want to disempower them
- they are the experts on their own needs
- social worker is aware of all the legislation that is around
- they don’t assess people so that they fit into services (assess needs; best ways)
- community care act = enable people to stay at home (?)
- two sets of needs there (carer and cared-for)
- physical needs, etc (?) usually for cared-for
- stress is a big thing with carer
- after 1990:

you would listen to both and try to arrange services that would benefit both people
 discrepancy between carer and cared-for (how can you help both?)
 1995 (another law): Carer's Recognition and Services (?) – Carer's Act of 1995
 entitled carer's to have an assessment in their own right
 problem: carer had to ask for one (don't know what is carer; what is assessment)
 many of them didn't get assessment (too hard to comprehend situation)
 only could ask for assessment if person they were caring for was receiving assessment
 2000 Carer's and Children's Act:

duty social service team is the team that initially goes out to perform assessment
 deal with going into short-term assessment
 there is also a long-term team for longer periods (another social worker picks up)
 few years back:
 social workers develop longer-term relationships and basically provide support

referral from duty social worker will be allocated and moved on to social worker
 criteria: urgent, etc
 if referral involved person that was already well known by social worker:
 their data is passed on.

“partnership” between social worker and carer
 equal member; equal footing
 not to involve anybody else

exchange process
 identify somebody's needs through this process

older people
 think about welfare
 don't think about residential homes – more about group housing
 some don't want to be involved – their pride is undermined
 social worker must not undermine person
 see s.w. as interfering in lives
 any good social worker will be there to work out the balance; provide independence

after assessment
 put together care plan – specific goals; services
 sometimes no end point can be seen
 persons are not always independent – care plan is almost “dictating”
 social workers should review at regular intervals
 are persons more or less independent
 workers alter the care plan accordingly
 not happening as much as could be – not enough social workers?

when they're eligible they get a referral

Bowens area:
 talk to liz honey (personal recommendation)

questionnaires
 much better response from older people when you talk to them face to face
 can't always get out information you want with just a question
 can they trust what information they are giving you?
 your motives?
 what is it that you are looking at?
 who are you?
 on whose behalf?

what is information going to be used for?
plain English

she was at day centre:
forms often don't come back
"oh no, not another one"

see if carer support networks can give you information that they already have
carer support merton
merton mind

Merton Carers Assessment Audit

Naveen Selvadurai, Steven Posnack, Brian Jaeger, Patrick Faiola

Interviewee	Gifford House (various)
Title (e.g., Head of Community Care)	
Department / Organization	(Older People's Referrals)
Phone Number / Email	
Interviewed by	Naveen / Steven
Date/Time	21 January 2002
Location	Gifford House
Topic (description)	

Charles (ext 4388) informed us about a contact for the Housing teams:

Mr. Denis Bloom
Tel: 8661 1734

(Mr. Bloom is the ex-husband of a tenant in Trellis House. He is a retired architect. He would be happy to meet with a researcher about supported housing.)

introductions/those present:

Charles Bowens
Liz Honey
Catherine Gard, Social Worker
Jean Spencer, Manager

getting names off of computer software?

three other sources of getting referrals

crossroads
merton minds
some sort of survey of current open cases to social workers here

Liz:

certainly not 500 available since November (since new forms)
how many people, estimate? not sure
couple of months too early with this project
nobody even knew about it – but yet we had to be implementing it

since start of financial year last april:

only about a 150
only names of clients; will have to go through files to see who the carer is

been in this response situation before? what is the best method of reaching most people (> responses)

Tamsin white:
did survey last November – can give you estimate on how many responses

phoning the client (therefore higher response rate)
carer support merton:
much wider spread of people
poor response could also mean that those ppl are not here
died
moved

maybe we should expand to:
anybody who's had an assessment as a carer
you could extrapolate the people who are aware of the post-November issues

a lot of carers are also stressed
no time or energy
not wanting to complete forms that don't give them benefit
follow up form? telephone call?

also go to
Merton MIND (most already assessed)
crossroads (not necessarily)

forget about 2000 act
a lot of people who've fallen under that probably wouldn't even recognize it; we explain principle of act to carers – we have an administration problem at present which is hopefully being addressed about how the assessments are currently recorded

assessment and information coordinator
Teresa Temple
ext 4367

questionnaire:
if you are no longer caring for the person, still fill it out "for the past"
or: if you are still caring, answer this question.

switch tactics:
feasible to telephone people? answer question over the phone?
ask Tamsin about the telephone survey
usually council officers that telephone
usually send letter first saying that they are going to telephone
much easier for people to decide in advance whether 'yes' or 'no'
could send a copy of the questionnaire as well – they've got it as well
they've got the questions; you can say you could return this in writing also!
easier because we could directly input into the computer – speeding it up
this is for Colin to sort out
is giving telephone number out subject to data protection too?

crossroads is also subject to similar legality and data protection

active carers
we have the list of carer names

referrals
we only have the cared-for list – must look up each file and then determine carer
couldn't bank on it – maybe 4 cases out of 5

Geoff Davy (IT)
knows how to extract data from database

next

they'll ask Teresa what they can provide
we should try to sort out data protection issues

Merton Carers Assessment Audit

Naveen Selvadurai, Steven Posnack, Brian Jaeger, Patrick Faiola

Interviewee	Elizabeth Honey
Title (e.g., Head of Community Care)	Duty Team Manager
Department / Organization	Gifford House
Phone Number / Email	
Interviewed by	Naveen / Steve
Date/Time	29 January 2002
Location	Gifford House / Carer's home
Topic (description)	Assessments

Liz helped us cross-reference the cared-for information in order to find the carer (or next-of-kin). we tried this on the computer and then by using the physical files in their storage room.

Obtained a copy of the result set on disk from Teresa (IT) so that it's easier to manage on our end.

Went to a carer's assessment with Liz:

Cared-for (?) – 93yrs

Carer: son Peter James cares for her (50yrs?)

he has problems too

Crohn's Disease

gallstones

going on vacation/break for 3.5 weeks – Thailand

providing respite care during break

has children but not in "caring" role with regards to them

lives onsite (upstairs)

works 8-6; cares rest of time

"both need complete looking after"

purpose of this meeting:

carer's act assessment

register son as carer

council recognises both people

cared for kept making/adding comments

gave input to many questions

Liz: their choice whether cared-for stays or not; does add bias but can't be perfect

Liz: we give carer option of completing assessment on their own

more time to think, better answers

"stressed" carer question

cared-for didn't seem to mind carer responses

frustration

some questions asked – redundant?

like the "social life" question

Liz: we must ask them anyway to get them thinking along those lines

Merton Crossroads – January 21, 2002

Moray Holbrook

They are in the voluntary sector; however, their care support workers are not volunteers, they are paid individuals that provide a break to the carers in Merton. These men and women are trained to be able to care for people with physical disabilities, terminal and life threatening illnesses, adults and children with a learning disability and the elderly.

Breaks - their services are referred by Social Services, district nurses, and self referrals.

The organisation pays 22 carer support workers to provide breaks to Carers. Their services include a 2-3 hour a week break, full weekend breaks every couple of months, 10 hour a night breaks up to 3 nights a week to allow carers to receive a full night sleep.

The managers are paid staff that provide the people seeking assistance with their own assessment. They provide a home visit to the carer, never asking for their financial information.

The Carers do not necessarily want Social Services knowing of their financial standing. These people often save their money for services such as funerals as not to burden others; therefore, they do not want Social Services finding out about their few assets. Crossroads does not perform a financial assessment, and therefore the carers do not mind their assessment process as much. Every person who receives an assessment is visited by the appropriate staff managers to ensure these people qualify for the service.

They are a very small organisation providing as much assistance as the can. They have a waiting list for people to start taking advantage of the service.

The only service that Crossroads cannot provide in place of the carer is to give medication. Their staff are not qualified nurses.

Often if the Manager providing the Crossroads assessment seems to think the Carer might need more support, with paperwork/benefits, help from Social Services, they refer them to Carer Support.

Crossroads sends the same staff member to each carer to enable the cared-for to build a relationship with the care support worker while the carer goes out and can live his/her own life for a few of hours a week. Merton Crossroads believe that this is good for both people and does benefit the carer and cared-for.

Since the support staff are paid for their services, they are a reliable commodity. They will be around every week providing a reliable service that the carer can count on.

Support staff - All police checked. Constant on going training, trained in Moving and

handling course/ hoists if necessary. Rolling program of training, 7-days. Shadowing others. They can undertake specialised tasks for example physiotherapy exercises after a demonstration from the qualified professional.

This document was modified after inspection by Moray Holbrook

Merton Minds Meeting - January 29, 2002

Geoff Spencer/Margaret Crouch

Margaret runs the Carer program on Tuesdays.

Under Social Services Merton Mind Provides the following services:

1. Day Centre
2. Open House
3. Help for Carers
4. Outreach.

The Open House is run on Tuesdays. It is a way for Carers/Cared-For to get out of the house and speak to other people in very similar situations. The open house is used as a gateway into the other services that Merton Minds provide.

Social Services cannot access a the cared-for with dementia without going through a carer.

While at the open houses, carers quite frequently realise that the cared-for can be left alone without them for a little while.

Attendance at the open houses is never 100%; however, it is a service that the people look forward to all week, and there is always a fairly high turnout. Often the people attending are able to remain active until they either pass away or are physically unable to continue attending.

Just about all people taking advantage of Merton Minds are already in the Social Service system. Many of the Carers do not know that they are able to obtain an assessment in their own right.

Geoff mentioned that he feels that the staff at Merton Mind are trained to work with these people with dementia. The social workers providing assessments to the carers and their cared-for are not necessarily experts on the subject of dementia. He believes that the assessments might be better provided and more accurate, if they were able to provide the people with elderly dementia with the assessments.

Margaret Crouch
19-02-02

Carer Support Merton - January 31, 2002

Eve, Irene, Christine

Carers Support Merton (CSM) is a registered charity which provides advice, information and support for unpaid carers of people who are ill, disabled or frail. Carers contact CSM to find out what services are available to both themselves and the people they care for, particularly when a crisis occurs and they have no idea where to turn to for help. Only about 50% of people who first make contact with CSM are aware of the services which are available, or the role of social services.

CSM always tell carers that they are entitled to an assessment in their own right – the Carers' Assessment – which is separate from the assessment of the person they care for. Many carers are unaware that they are entitled to their own assessment, or that they (and their cared-for person) can apply for a re-assessment should their circumstances change.

Social workers today are frequently overwhelmed with paperwork, and once a care package of assistance has been put in place, the case is then closed. The case will not be re-opened unless the carer or cared-for person makes contact again, requesting more assistance.

Most organisations which have contact with carers/cared-for (social services, OT, the various health professionals) make their own assessments and have their forms/paperwork. There has been discussion in the borough around the possibility of a single assessment form to be used by all agencies involved in a particular case. The workers from CSM expressed reservations about whether this system would be workable – there would be a very real possibility that documents would get lost and that the time taken to pass the form around between the different professionals might seriously delay assessment of need and services being put into place.

There was also discussion around new legislation, how and if it has been of benefit to the carer and how few changes have actually been implemented. A real difficulty is that legislation gives local authorities powers to do things, but it does not make such provisions compulsory. There is also concern that councils will choose to provide services to the Carer or cared-for on the basis of who is the most able to pay, rather than based on need.

Services within the borough are so tightly stretched that there is often simply not enough provision to respond to the level of demand or need. This leads to 'tightening-up' of criteria and for services to be only allocated to those in greatest need, meaning that people who do not meet the stringent criteria do not receive any services at all and 'fall through the net' of service provision.

Demand for respite care is very high, but there are many conditions around respite care, and there is very little provision within the borough. Similarly, there is little in the way of day care provision – many day centres have been closed down and this has caused problems with the people who previously used them, particularly adults with a learning disability. In these cases, the adult with a learning disability attending a day centre was a form of respite for the carer. When the centre closes they find themselves with multiple problems – people with a

LD need structure and routine in their lives and it may take them a long time to adjust to their new circumstances. Carers take the brunt of these consequences in addition to losing the little time they had to themselves.

There is also some disparity between the respite services which carers actually want and those which are offered. Crossroads services are seen as particularly valuable, but demands on the service mean it cannot offer the flexibility most carers would like. Similarly, carers have told CSM workers that they would like greater choice – many would prefer a whole day service rather than the full weekend which is currently on offer, and some would like the opportunity to go away with the person they care for, rather than having to take separate breaks.

One of the greatest problems associated with caring is isolation – social networks dry up, there is no money to spend on outings and it can be very difficult to leave the person who is being cared-for, and subsequently carers grow increasingly isolated and depressed. Many carers do not receive an assessment. Older people are often reluctant to seek assistance from social services. They were brought up to be independent and cope with their problems themselves, and despite having paid into the system for most of their lives, they are unwilling to ask for or accept what they perceive to be ‘charity’. There is also an element of fear and misunderstanding of the role of social services, and they are often concerned that if they ask for help, the person they are caring-for might be taken away and put into residential care against their will. This attitude is far less prevalent in those under 40, who are far more aware of their rights, less respectful of ‘authority’ figures and able to demand the services they feel they are entitled to. It is a sad fact that those who make the most fuss frequently receive the most services.

There are reservations about the new carers’ assessment, and whether it is little more than a paper exercise. Certainly up to November of last year many carers were still not being offered the assessment, and being assessed does not automatically guarantee the provision of any services. At least one case has been reported to CSM of a carer asking for a carer’s assessment, and the social worker not knowing what that was.

Services that have been identified which could be valuable to carers in LB Merton:

- a programme dealing with early dementia
- respite for adults with mental health problems (not dementia)
- a voluntary sitters scheme
- more flexibility around respite care
- transport services (dial-a-ride is generally seen as unreliable)
- a programme for other ex-carers similar to Merton MIND’s ‘Next Step’ programme
- a while day respite services to allow carers a full day out

Modified after examination by Eve Brimacombe

Appendix F – CARER ASSESSMENT PROTOCOL

6. ASSESSMENT

N. CARERS' ASSESSMENTS AND SUPPORT PLANS

There are three pieces of legislation which have relevance: The Disabled Persons (Services, Consultation, and Representation) Act 1986, the Carers (Recognition and Services) Act 1995, and the Carers and Disabled Children Act 2000. The applicability and definition of carers is not consistent between these pieces of legislation.

The DC(SCR)A 1986 applies only when a disabled adult is being assessed, where it is the duty of the assessor to have regard to the ability of the carer to continuing to provide care irrespective of any request made by the carer.

The C(R&S)A 1995 enables all carers to request and assessment of their current and future ability to provide care. This assessment is to be taken into account when a local authority makes its decision on the type of community care services to be provided to the person cared for. This assessment relates to the carer's ability to provide care and to sustain that role but does not provide for support to carers in their caring role.

The C&DCA 2000 gives local authorities the power to supply certain services directly to carers following an assessment; and enables local authorities to make direct payments to carers (including 16 and 17 year old carers) for the services that meet their needs.

A carer's assessment under the C&DCA 2000 is carried out at the request of the carer in order:

- To determine whether the care is eligible for support
- To determine the support needs of the carer (i.e. what will help the carer in their caring roles and help them to maintain their health and well being)
- To see if those needs can be met by social or other services.

A carer's assessment should be focused on what the carer identifies as the best possible outcome. The best possible outcome will depend on the impact of caring on the particular carer. This impact is also the best test for "regular and substantial" caring

The duty to assess arises if the care requests and assessment but ***all carers should be made informed of their right to request an assessment and be actively encouraged to be assessed*** in order that their views may be fully incorporated in to the assessment process. In situations where a carer opts not to be assessed, the fact should be recorded on an officer report sheet along with the reason (if it can be determined) and held on the user's file.

The needs of cares must be taken into account in determining the overall assessment of need of a user. Whilst and assessment under the C (R&S) A 1995 feeds into the

assessment (and care plans) of the cared for person, assessments under the C&DCA may lead to a carer's support plan, with provision of services to the carer in their own right.

In the context of a carer's assessment, a carer is a person (aged 16 or over) who may or may not be a relative and who may or may not be living with the person for whom they are caring. Paid care workers, volunteers from a volunteer organisation and ones providing personal assistance for payment (either in cash or in kind) are excluded from this definition.

A carer is entitled to an assessment if the are:

- a) providers or intends to provide a substantial amount of care on a regular basis for another individual aged 18 or over
- b) asks a local authority to carry out an assessment of his ability to provide and to continue to provide care for the person cared for, and
- c) if the local authority is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services.

A person may request an assessment if he/she is not yet a carer but intends to become one in the future, for example when a relative is being discharged from a hospital who will need a substantial amount of help.

The words "Substantial" and "regular" are subject to local interpretation and should not be considered in just quantitative terms. Individual circumstances need to be taken into account as substantial may refer as much to the impact of caring on an individual as to the number of hours they spend actually caring. This is particularly the case in situations that may require intermittent, high intensity or high-risk involvement.

Carers should either be given the options of either completing and submitting their own assessment or completing an assessment with the professional if they prefer.

All carers who are assessed (including those who choose to self-assess) should also be provided with a risk assessment.

Carers' assessments should focus on what the carer wants to happen (the outcomes). It should consider the following modules (drawn from A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000, published by DoH)

1. Carer's role
2. Breaks and social life
3. Physical well being and personal safety
4. Relationships and mental well being
5. Care of the home(s)
6. Accommodations
7. Finances
8. Work

9. Education and training
10. Current practical and emotional support
11. Wider responsibilities
12. Further caring role
13. Emergencies / alternatives arrangements
14. Access to information and advocacy

Once assessed, carers may be given services in their own right. In order to receive services, they need to meet the carers' eligibility criteria. If they are eligible for services, these should be recorded on the carer's support plan, describing both the outcomes required by the carer and services which will provide support.

Carers' assessments should be held on User's file unless the carer is provided with a community care assessment in his/her own right or where a service is provided to the carer in his/her own right under the provisions of the Carers and Disabled Children Act. In this case, the carer will need to have a separate file drawn up.

In situations where Users are also carers and are provided with carer's assessments, copies of their carer's assessments should be held on both their own file and that of the person they care for. Their personal assessment of their own needs should only be held on their own file.

It is important to cross-reference local procedures and guidelines by user group in considering the needs of carers. For example, carers of adults with mental health needs should be considered in terms of the National Service Framework for Mental Health which provides for the annual assessment of all carers of people with severe mental health.

The carer's assessment will ordinarily be undertaken by the staff / key worker who knows the user / cared for person. Where the cared for person is not a user, the assessment will be the responsibility of the team who would have responsibility if the cared for person were being assessed.

Appendix G – CARER ASSESSMENT FORM

HOUSING & SOCIAL SERVICES DEPARTMENT
 Director of Housing & Social Services - Rea Mattocks



CARER'S ASSESSMENT (MA 5)

A carer is a person (aged 16 or over) who may or may not be a relative and who may or may not be living with the person for whom they are caring. Carers are entitled to have their own needs assessed if they are giving or intending to give regular and substantial care and are caring for a person who is, to the satisfaction of the local authority, someone for whom it may provide or arrange for the provision of community care services.

Carers who are paid, who work for a voluntary organisation or who are not providing or intending to provide regular and substantial care will not be entitled to an assessment.

As a Carer you may complete this form on your own behalf, or be assisted by a Community Care Assessor. **It is important that we are aware of your needs and views so that we can help the person you look after in the best way possible.**

If you would like someone to assist you with your assessment, please could you discuss this with the person who is assessing the person you look after.2

Alternatively, please contact :

Assessor's Name:	_____	Tel:	_____
Office Address:	_____	Fax:	_____
		Email:	_____

If you choose to complete your own assessment, please return it in the envelope provided. You do not need to attach a stamp.

*For further information, please refer to the information booklet
 "How to get help if you are looking after someone"*

Details of Carer	
Address:	
Post Code:	Date of Birth (if under 18)
Name of the person you look	
Address of the person you look after if they do not live with you:	
	Post

Details of the Care you Provide		
<i>Please circle the appropriate answer</i>		
Is the person you care for being assessed or re-assessed?	Yes	No
If not, do they need to be assessed or re-assessed?	Yes	No
Are you paid for the care you provide? (<i>Do not include state benefits</i>)	Yes	No
Are you working as a volunteer for a voluntary organisation?	Yes	No
Does anyone else help you to provide care to the person you look after?	Yes	No
If you answered "Yes" to the above question, please give details:		
Do you care for anyone else? (e.g. children, family)	Yes	No
If you answered "Yes" to the above question, please state who:		

How Much Care do you Provide? (approximately)		
<i>Please tick all boxes that apply</i>		
Daily	<input type="checkbox"/>	If daily, how many hours on average?
Weekly	<input type="checkbox"/>	If weekly, how many days per week
Monthly	<input type="checkbox"/>	If monthly how many days per
Less than Monthly	<input type="checkbox"/>	If less, how many days per year?
Other (Please give details)		
If you live with the person you care for, do you get woken up at night?	Yes No	If Yes, How often (e.g. every night, weekly, monthly)
Please tell us briefly about what you do to help the person you look after.		

Needs of the Person you Care for							
1. Does the person you care for live with you?		Yes	(Go to question 2)		No	(Go to question 3)	
2. Are there any problems with your accommodation? (e.g. overcrowding, problems with stairs or accessing the bathroom)							
3. Do you have any problems in getting to see them? (e.g. transport, distance)							
4. Have the care needs changed recently?		Yes	No	5. Is this causing you a		Yes	No
If the answer to question 5. is Yes, please give details.							
3. Does the person you look after receive any services? (e.g. home care, day care, nursing care). If Yes, please give details.					Yes	No	

Your Needs							
Are you finding it difficult to look after the person you care for?					Yes	No	
If yes, what are the main problems? (e.g. stress on family life, financial problems, problems with work or your social life)							
Are you in good health?					Yes	No	
If No, is this causing you problems in providing care for the person you look after?					Yes	No	
How does this affect you and them?							
Are you or might you be at risk of any of the following?							
Physical harm or violence from the person you look after		Yes	No	Any form of abuse - verbal or financial		Yes	No
Stress or emotional problems as a result of caring		Yes	No	Physical injury (e.g. back damage through lifting)		Yes	No
Are you worried you may hurt the person you look after?		Yes	No	If yes would you like a Carer's Risk Assessment ?		Yes	No

Signed: _____

Date: _____

If caring for the person you look after is causing you any problems not mentioned above please use this space to tell us about them and what you think would help you to continue caring.

OFFICE USE ONLY
Carer's Support Plan

Outcome(s) required by Carer:

Services

Appendix H – CARER DEMOGRAPHICS (LB HARINGEY)

Table 1: Estimates of numbers of carers aged 6 and over, and as a percentage of the population, 1999

	Men	%	Women	%	Total	%
Haringey	8,620	10.5	12,250	13.5	20,870	12.1
Inner London	110,440	10.6	155,530	13.5	265,970	12.1
Outer London	195,720	11.5	268,880	14.8	463,590	13.2

Source: ONS General Household Surveys, and LRC population projections

Table 2: Estimates of numbers of carers aged 16 and over by age, 1999

Age Group	Haringey %		Inner London %		Outer London %	
16-17	280	1.34	3,330	1.25	6,530	1.41
18-19	380	1.82	4,460	1.68	8,590	1.85
20-24	1,030	4.94	13,000	4.89	19,910	4.29
25-29	1,350	6.47	17,750	6.67	22,840	4.93
30-34	2,140	10.25	27,490	10.34	36,240	7.8
35-39	2,500	11.98	31,930	12.01	47,020	10.14
40-44	2,290	10.97	29,230	10.99	49,970	10.78
45-49	2,380	11.40	29,810	11.21	56,270	12.14
50-54	2,500	11.98	31,110	11.70	63,270	13.65
55-59	1,780	8.53	22,060	8.29	42,590	9.19
60-64	1,520	7.28	18,960	7.13	37,120	8.01
65-69	1,080	5.17	13,700	5.15	26,850	5.79
70-74	750	3.59	10,590	3.98	20,690	4.46
75-79	520	2.49	7,530	2.83	15,360	3.31
80-84	240	1.15	3,410	1.28	6,960	1.50
85+	120	0.57	1,600	0.60	3,290	0.73
Total	20,870	99.95	265,960	100.00	463,600	100.00

Table 3: Estimates of carers aged 16 and over by ethnic group, 1999

Ethnic Group	Haringey %		Inner London %		Outer London %	
White	16,060	76.95	215,190	80.90	392,710	84.71
Black Caribbean	1,580	7.57	14,710	5.53	10,520	2.27
Black African	770	3.69	7,250	2.73	4,510	0.97
Black Other	460	2.20	4,420	1.66	2,820	0.61
Indian	780	3.74	8,290	3.12	32,340	6.98
Pakistani	110	0.53	2,100	0.79	4,890	1.05
Bangladeshi	100	0.48	2,330	0.88	590	0.13
Chinese	160	0.77	2,090	0.79	2,400	0.52
Other	850	4.07	9,600	3.61	12,810	2.76
All Groups	20,870	100.00	265,980	100.00	463,590	100.00

Other sources of information about carers include a 1999 Haringey Council postal survey of 289 known carers identified through the carers' register and voluntary organisations. We received 81 responses from carers living in the borough, which has provided the following picture:

- Over 60 per cent of carers are women
- 50 per cent are aged 60 years and over
- 50 per cent of carers are retired
- 24 per cent were unable to work because of their caring commitments
- Only 4 per cent of carers are working - half full time and the remainder part time

The 1991 Census found that approximately 43 per cent of the local population were from black and minority ethnic groups; the Haringey Council survey found that 46% of carers were from these groups. The survey identified Caribbean/West Indian, Irish and Asian carers.

The Mental Health Carers Support Association estimates that there are up to 300 carers supporting people with mental ill health in the community. The association works with 85 carers to provide information, advice and support.

The Haringey Young Carers project was established after a survey of local schools have estimated in excess of 130 carers under the age of 18 living in the borough. (This is a much lower figure than that estimated by the LRC for 1999 who gave 280 as the estimate for those aged 16-17 alone.) Although we are unsure about the exact number of young carers (under 18 years) in the area, Haringey Young Carers project have received over 140 referrals since August 1998 and over 90 young carers have used their services in that time. Of the 90 young carers using the project 51% are boys, the majority are aged 8-15 years (although eight are aged 5-7 years), they come from a range of ethnic backgrounds (only 25% are white) and 67% are caring for their mothers.

The 1999 Haringey Council survey showed that approximately half of the carers who responded to the survey have been caring for over 20 years. The longest length of time caring was 51 years. Carers most commonly received support from friends and relatives, their GP, other carers and the person they care for.

Haringey Council is planning to update the council's carers' register, which will keep an up to date as possible record of the carers in the borough.

Glossary

assessment - a review of a person's needs that is performed by a professional social service worker.

assisted living facility - a licensed home that offers private apartments; services provided include meals, transportation, group activities and medical support.

breaks - opportunity given to a caregiver for some time off from their caring responsibilities.

caregiver - a person who provides physical, emotional and/or financial assistance to another individual who is disabled or suffering from an illness; also known as a carer.

community care - care that is given as a mix of health and social support to individuals within a community.

employee-assistance program - assistance provided by the employer to persons working in the company; assistance can come in the form of financial aid, counseling, breaks, referrals and networking opportunities.

housekeeper - also known as a chore worker; performs minor duties around a cared-for person's household such as garbage handling, housecleaning, etc. (In-Home Services, November 2001).

meal-delivery service - service that home-delivers meals to elderly or disabled persons; sometimes services such as shopping, nutrition classes and counseling are provided.

nursing home - care facility that provides long-term care to the elderly or to those who are suffering from an illness.

respite care - a service that provides caregivers with temporary relief from their caring responsibilities; skilled social service workers take over the responsibilities for a short period of time.

retirement community - group housing facilities for the elderly; each responsible for their own needs.

sitting service - service provided by social services or by a private company; attempts to provide day-care or house-sitting capabilities to those in need of such services.

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