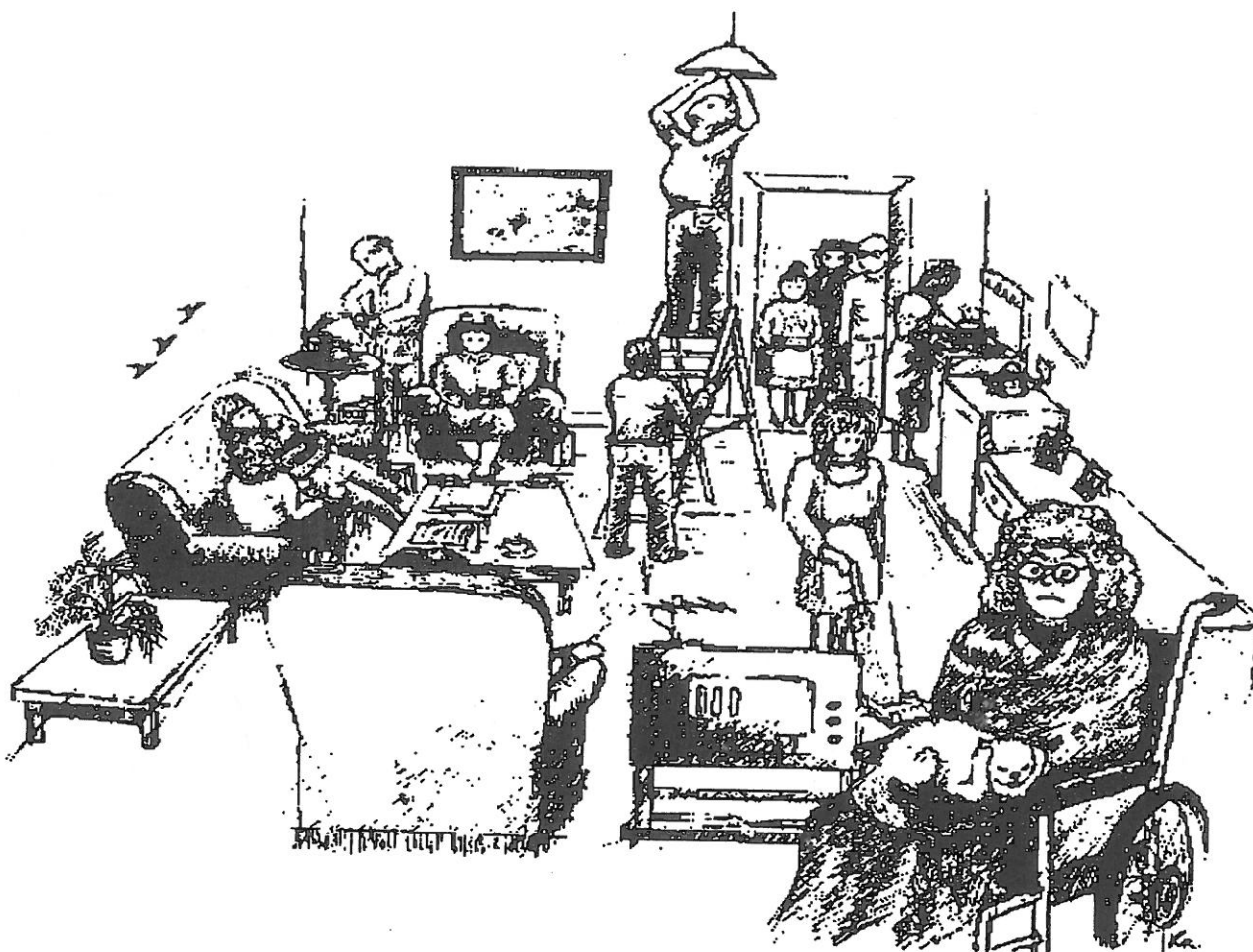

Caring Networks



A study of the views of people receiving a Home Help service

by

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Lothian Regional Council
Department of Social Work
August 1990





APPENDIX 1

LOTHIAN REGIONAL COUNCIL DEPARTMENT OF SOCIAL WORK

JOB OUTLINE

Section: Field Services
Post: Home Help
Responsible to: Area Home Care Organiser

PURPOSE OF JOB

Home Helps are part of the Home Care Service. They work as part of the local Social Work Area Team. Home Helps are responsible and accountable to the Home Care Organiser/Assistant Organiser for the day to day duties they are required to perform and to carry out the instructions of the Home Care Organiser/Assistant Organiser in the performance of these duties.

Home Helps are employed to work with elderly people, with chronically sick and disabled people, with mentally handicapped people and with families experiencing social problems. They are also expected to provide assistance to women and their families at the time of a new birth. They may undertake all or some of the following duties where the client or the client's family is unable to do so and where there is no risk to the worker's health or safety in doing so.

MAJOR TASKS/JOB ACTIVITIES

PRACTICAL TASKS APPROPRIATE TO HOME CARE

1. The ordinary running of a client's household; shopping, collecting pensions and prescriptions, cooking, washing, ironing, mending, general bed making, attending to fires and boilers, and other domestic duties such as dusting and vacuuming floors.
2. Home Helps will normally clean all inside windows and any/outside windows which can be cleaned without any risk of injury.
3. In exceptional circumstances, Home Helps may take their client's turn on a rota for cleaning common stairs and passages, where there is no relative available to undertake the task.
4. Home Helps will not be expected to clean infested houses. If a house is particularly dirty and continuing personal care will be offered to the client, the Organiser will assess the state of the house and will make appropriate arrangements to have it cleaned by more than one Home Help.

CLIENT CARE TASKS

1. Home Helps will be expected to undertake a range of personal caring tasks in a sympathetic and responsible manner. These may include dressing, washing and feeding their clients.

2. Home Helps will not be expected to bath their clients but may be asked by the Organiser to provide simple forms of assistance to the client who chooses to take a bath during the Home Help's visit. Assistance with hairwashing, shaving and other aspects of personal hygiene may be required.
3. Home Helps must not under any circumstances undertake nursing duties, but they may be required by the Organiser to empty commodes and handle incontinent laundry.
4. Home Helps may, however, assist clients in the taking of prescribed drugs and medicines, following the dosage instructions indicated. If in doubt, the Home Care Organiser, Community Nurse or General Practitioner must be consulted.
5. The changing of oxygen cylinders may be undertaken but only by those members of staff who have received special training.
6. Home Helps are required to prepare meals for clients when necessary. Clients should be consulted about their dietary habits. Where clients require special diets, the Home Care Organiser should be consulted to obtain advice from the Community Nurse or Dietician.
7. Home Helps who are attending maternity cases, or families, may be asked to care for children or other members of the client's family.
8. Nail cutting may be undertaken but only by Home Helps who have received special training.

SOCIAL TASKS

1. Home Helps will be expected to talk with their clients about daily events and to help them to maintain contact with family, friends and community.
2. Home Helps should aim to create a supportive, homely atmosphere where clients can achieve maximum independence.
3. Following consultation with the Home Care Organiser, Home Helps may be asked to assist their clients in suitable leisure activities and to accompany socially isolated clients on visits outside their homes, to the shops or the library for example.

GENERAL TASKS

Such other appropriate duties as the Director of Social Work or his nominee may determine.

SUPERVISION RECEIVED

Given the isolated nature of the work, Home Helps will be given appropriate and regular supervision during their working hours.

In addition to regular supervision, Home Helps will have access to advice and support in case of emergency.

CONTACTS

The Home Help is expected to be a member of a caring team, liaising with other services, relatives and neighbours as necessary.

EDUCATIONAL/VOCATIONAL QUALIFICATIONS REQUIRED

Although no formal educational qualifications are required, it is expected that all Home Helps will have a basic level of literacy and numeracy. All Home Helps will be given training opportunities throughout the course of their employment. They will be required to attend those courses which are offered during their normal working hours and which are considered by their Organiser as being appropriate for them.

EXPERIENCE REQUIRED

Home Helps will normally be expected to have the important experience of caring for others, e.g. relatives and to have the experience of running a home.

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In addition, we owe thanks to Anne Anderson, Regional Officer (Elderly), who suggested the idea of a consumer survey; Agnes Matthews, Community Worker, who influenced greatly our thinking on networks, worked with the area team on the community profile and provided useful papers and references; the Home Care Organiser who cooperated and contributed as a member of the research team; Kristine Redman who created the cartoon for the front cover; and the typing pool at Tayside RHQ who typed the final report.

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Julie Ridley and Margaret Macdonald

18 July 1990

1. INTRODUCTION

BACKGROUND

Research on the Home Care Service is dominated by the views of professionals. The main focus of attention has been the changing role of home helps and management of the Service (for example, SSI, 1988 "Managing Policy Change in Home Help Services" and "A Management Checklist of Home Help Services"). Few studies have concentrated on the direct experiences of service users and their carers. Where recent studies exist they have been about clients' perception of their needs and abilities connected with the practical tasks undertaken by home helps and home help aides (Janet Monk, 1987, "Consumers Opinions of Home Helps, Home Care Aides and Meals on Wheels", Derbyshire SSD) or assessing user satisfaction with a range of domiciliary services (East Walthamstow SSD, 1988, "Report of a Consumer Survey of Services to Elderly People"; NOP Market Research Limited, 1988, "Home Help Survey", Buckinghamshire County Council).

The incentive for a user views survey in Lothian was stimulated by the recent national debate on domiciliary services: The DHSS, Social Service Inspectorate reports in 1988 and more recently by Sir Roy Griffiths' "Community Care: An Agenda for Action" and the subsequent Government White Paper 1989 "Caring for People". Both the Griffiths Report and the White Paper emphasise the importance of developing a range of domiciliary services to support people in the community and the responsibility of social services/work departments to receive comments from service users and take carers' needs into account. The need to focus on social networks and informal carers has been a consistent thread running through other major legislation and reports, for example the Seebohm Report, 1971 and the Barclay Report, 1982.

In Lothian, the Joint Planning Team (Elderly) in implementing the recommendations of the 1986 Working Party Report "Partners in Care" and staff attending cross branch meetings organised by the Social Work

Department have highlighted the importance of consultation with service users (Sue Brace, Stewart Black, "Responding to Old People: Papers from a Departmental Policy and Practice Seminar").

An important influence on the evolution of this project was the knowledge from past research that it is notoriously difficult to obtain users' views of their true feelings about services but more particularly about the kinds of improvements they would like (Social Services Research Journal, 1989, Macpherson, Hunter, McKeganey "Interviewing Elderly People: Some Problems and Challenges": Janet Monk, 1987, Derbyshire SSD).

AIMS AND OBJECTIVES

The main aim of the survey described by this Report was to gain an understanding and appreciate the feelings of service users and their carers about community care/support, with a particular interest in the contribution of Home Care Services and for service users' views to influence changes in Home Care practice.

Its objectives were: -

- to research service users' viewpoint;
- to look at individual networks of community care and the role of Home Care in this;
- to explore the partnerships between agencies and informal carers providing "care packages";
- to be able to offer suggestions for improving Home Care by making the service more user-orientated;
- to increase user control over the care received;

- to be able to look at the policy implications for Lothian Social Work Department of providing care packages for very vulnerable people in the community.

RESEARCH METHODS

This research project concerned home help clients of one local area team in Lothian which had been developing a community work approach to working with elderly people. A research team was set up consisting of a research and development officer, a seconded researcher, a community worker and the area team's Home Care Organiser which acted as a steering group for the project and engineered its design.

Being influenced by other research into the views of service users (for example, Johnson et al, 1981, "Ageing, Needs and Nutrition"; and Brandon & Ridley's research in 1987, "Beginning to Listen") it was decided to employ qualitative research methods and survey a small sample of service users. The main part of the project was informal interviews with clients in their own homes and in addition carers (where identified) were asked to complete a short postal questionnaire. Informal interviews with a small number of people offered a way of looking in greater depth at the caring networks operating for people in the community, the different elements of a care package and people's views of the care they received. A conversational approach to interviewing was adopted using an interview schedule as a guide to the key areas for discussion. This was felt to offer greater control for the service user over the direction of the research interview by allowing the interviewee, and not the researchers, to set the tone and agenda of the conversation.

It was envisaged that an effective way of helping people focus on their requirements and priorities was to ask them about their daily routine and to identify their support networks. It was hoped that from this it would be possible to begin to sketch out each individual's support network, illustrating the range of involvement of both formal and informal carers. Some literature, for example, Colin and Mog Ball, 1982 "What the Neighbours Say", usefully demonstrates that caring networks involve a number of layers. These graduate from

an outer layer of observant neighbours, who notice that a routine has been broken, for example, the milk has not been collected to the committed neighbour or relative who spends a considerable amount of their time caring for the person.

When selecting a sample of home help clients, it was the intention to focus on very vulnerable people living in the community, defined in consultation with area team staff as:

- elderly people over 75 living alone;
- people with Alzheimers or senile dementia;
- physically handicapped people with dependents;
- very physically handicapped people;
- people with learning difficulties;
- couples where both partners were vulnerable;
- elderly people who had recently suffered a bereavement.

A selection of just over 30 people was identified by the area team as "very vulnerable", although it should perhaps be noted that this categorisation was not always shared by the people interviewed. In January 1990 a letter was delivered to each person by the home help involved asking if they would agree to participate in the survey and to offer convenient times for interviews. Only two people refused an interview, both because of ill health. Interviews were arranged through the home help and took place in each person's home some time between January and February 1990.

A short questionnaire was devised for carers, ie relatives, friends or neighbours, mostly identified by the individual during interview or through area team records, and was sent to their home with an enclosed prepaid envelope. Nineteen questionnaires were sent out. The questionnaire asked about the relationship the carer had to the person, the support and care given, whether professional services had consulted them, their views of the present caring situation and what their own needs for support, information and advice were. It was designed following consultation with a member of the Association of Carers in Scotland and influenced by information/references provided by that group. The questionnaire was piloted prior to distribution.

LAYOUT OF THE REPORT

In addition to discussion of the material from the individual interviews and the responses to the carers' questionnaires which form the main bulk of this report, we draw on statistical information primarily from the 1981 Census and from area team staff to compile a community profile of the local area (see part 2). Part 3 presents a profile of the Home Care Team and the current users of the Service. The views and opinions of service users are commented on in Part 4, and the responses to the carers' questionnaire in Part 5. In "Conclusions - Aspirations Into Reality" in part 6, we discuss the main issues identified from the research and how these relate to the Government White Paper on Community Care. Finally we offer a checklist of key issues for the Home Help Service. Copies of the interview schedule used as a guide and the carers questionnaire can be obtained on request from Lothian's Research, Planning and Development Team. A brief bibliography is given at the end of the report.

The term "Home Care Service" used throughout this report refers to domiciliary and community care support provided by home helps, managed by a Home Care Organiser and Assistant Home Care Organisers. This is the term used by Lothian Social Work Department in preference to "Home Help Service". This may be different from the terminology and management structure adopted by similar services in other Regions.

2. COMMUNITY PROFILE

INTRODUCTION

It is hoped that the following community profile will provide a useful backcloth to the survey findings. The profile describes the five Home Care patches covered by the area team taking part in the research. To preserve the anonymity of the area team the patches are not referred to by name but numbered one to five.

The information presented has been drawn from statistical information based on the 1981 Census provided by Edinburgh District Council in the form of ward profiles and from a session held with the area team staff to identify resources and problems in the area. Statistical information was available from the Region but this did not lend itself very well to analysis by the five Home Care patches.

However, problems have arisen in writing up these profiles due to the fact that EDC Ward Boundaries and Social Work Department boundaries are not coterminous. Any figures given are therefore an approximation of the actual situation. In some cases ward boundaries overlap between two Home Care patches. The profiles below offer a general picture and point out interesting differences between the five areas but they have limitations.

PATCH ONE

This area has a high proportion of elderly people, and relatively high proportions of both pensioner and single pensioner households. Over a quarter of its population are aged 60+. In addition rates of unemployment are high compared to the rest of the City.

Most of the area's rented housing accommodation is provided by the independent sector: a mixture of private lets and Housing Association tenancies. However, the overwhelming majority of homes (70%+) are

owner occupied. The most common type of dwelling is in tenement flats. Sheltered housing units are provided by both the private sector and public sector. There are a number of hostels for single homeless people.

It is well served with local statutory provision including the area social work office, DSS, hospitals, nursery provision, an ATC, community centre and community resource centre. In addition, churches offer other possible meeting places, one providing the venue for a creche and a Chinese elderly support group.

On the negative side, there are few local food shops or public launderettes. Most facilities cater for needs of tourists due to the area's close proximity to the City Centre. However, public transport is available for those who are able to use it, linking quickly with the whole range of facilities offered by the City. The other main problem concerns the type of housing predominant in the area, ie pre-1919 tenement accommodation. Stairs present a problem for many elderly people and the fact that they can be uneven and poorly lit can cause major difficulties for increasingly elderly and frail people.

PATCH TWO

This area also has an increasingly high proportion of elderly people and relative to the rest of the City has a higher than average number of single pensioner households. It has a low rate of unemployment. There is a mixture of housing provision in the area, mostly in tenement blocks. The majority of properties are privately owned: over 80% are owner occupied. Council housing is provided in modern tenement flats and maisonettes built post-1960. Over three quarters of sheltered housing is provided by the private sector. There are some Care Housing schemes in the area.

In contrast to the previous patch, there appear to be better community facilities, particularly for elderly people. These include an elderly day centre, lunch club, dementia day centre, centrally located health

centre. In addition there is a primary school, launderettes and mother and toddler groups.

A variety of local shops cater for residents' needs, some will deliver to the person's home. In addition there are a number of recreational facilities close at hand: swimming pool, public park and gardens, bowling green, local pubs and cafes, library, community centre and theatre.

PATCH THREE

At least a quarter of the population are people aged 60 and over. Again the numbers of pensioner and single pensioner households are high compared to other parts of the City. Due to the close proximity of the area to the University a large proportion of flats are rented by students. There are few local authority dwellings except for sheltered housing units. The majority of accommodation is in tenement flats, mostly privately owned but there is also some specialised housing for disabled people provided by Housing Associations. The age of buildings in the area is a problem in terms of upkeep, common stairs, etc, for large sections of the community, particularly elderly people.

A number of local resources/facilities are available - eg schools, churches - but these do not cater very well for the needs of the increasingly elderly population. It is poorly served with lunch clubs, day centres, playgroups and other community activities. Isolation is thought to be a significant problem for many elderly people, particularly due to the lack of organised meeting places or services

PATCH FOUR

In common with the other patches there are high numbers of elderly people living in this area and a relatively small proportion of young families. The unemployment rate is low compared to other parts of the City. Pensioner households are the most common type.

The vast majority of homes (over 80%) including flats, tenement flats, and semi-detached houses, are owner occupied. Council housing is concentrated in tenements and a number of terraced houses. Most of these homes date between 1956-59. There are a few sheltered housing places provided by the private sector. Some places in private nursing homes are available.

However, despite a high concentration of elderly people, facilities for this group are poor. Local shops are scarce and there are few social activities, eg lunch clubs, day centres. In addition this is a hilly area which poses particular problems for frail elderly and disabled people. There are few if any launderettes.

Social isolation is a problem for single elderly people living in large old houses. Transport to the City is regular and therefore means that the variety of resources and facilities offered by the City are accessible to those who can use public transport.

PATCH FIVE

Although the numbers of elderly people are high in this area, there is also more of a variety of people of different age groups. Unemployment rates are high in certain sections of this area.

The area contains a mixture of housing types, although some are more concentrated in certain sectors. Council housing is predominant in one part whilst owner occupied tenement flats dominate another. Tenements pre-date 1919. There are also a number of modern multi-storey flats built between 1960-79. Sheltered housing places are provided by both public and private sector sources.

This is one of the larger patches and consequently contains a wide range of resources and facilities. Shopping and laundry facilities are numerous but are not evenly distributed across the area. There is a Cathedral which runs an active social and welfare programme. In one part there are parks and safe play areas for children and an adventure playground.

There are two community centres. For single homeless people there are several accommodation facilities, a day centre and information centre, and a lunch club. For children there is a primary school, nurseries and a youth club.

Problems in the area have been described by area team staff as relating to "genteel poverty" referring to the numbers of elderly people living in large old fashioned houses. In addition there is a transient population of single homeless people. As in other areas tenement accommodation poses problems for elderly residents, in terms of dimly lit and uneven stairs and general maintenance.

SUMMARY

Overall the area covered by the Home Care Team contains significant numbers of elderly people which confirms the Region-wide trend of increasing proportions of very elderly in the population (Lothian Regional Council 1986 Population Estimates). A common thread is the general lack of special provision to meet the needs of elderly people.

Community facilities and services vary greatly from patch to patch and do not appear to have developed to meet the needs of local residents in all areas. In some patches the influx of elderly residents caused by private sector sheltered housing developments is clearly presenting new challenges for local health and social services.

However, regardless of the range or quality of services and facilities on people's doorstep, mobility is still the key determinant of use. In other words a non-ambulant person or wheelchair user living in patch two is no better off despite the relatively good facilities available, than a person living in patch three, unless they receive help with transport and depending on the network of informal support.

The availability of good local shops and launderettes and other community facilities will affect the kind of home help service offered to clients in terms of the amount of time spent in the client's home as opposed to that spent at the launderette doing clients' washing or shopping. This will also affect how well formal services can intermesh with layers of informal and community support.

3. HOME CARE PROFILE

3.1 STAFF

Home Care Organisers 1
 Assistant Home Care Organisers 4 full time
 1 part time

Average client caseload for a full time Assistant Organiser = 184

Number of home helps on average managed by a full time

Assistant Organiser = 49

Number of Home Helps on 31.01.90 = 219

Table 1 : Numbers of Home Helps - Full Time and Part Time

Hours Worked Per Week		Total	Female	Male
(Full Time)	39	15	11	4
(Part Time)	20	203	203	0
(Casual)	9	1	1	0

Twenty home helps worked weekends, only one worked after 5.00 pm seven days a week. The majority of part time home helps worked from 9.00 am to 1.00 pm.

Staff Training as of February 1990

Home Help Organiser/Assistant Home Help Organiser

CSS 1

CQSW 0

In Service Course in Social Care 0

Home Helps: *

Induction Training All Staff

First Aid

Health and Safety

General Training

* Accurate records of training undertaken by home helps were not available.

Length of General Training Course = 5 x 1/2 days

Content of General Training:

- (i) The role of the home help
- (ii) Keeping the client independent
- (iii) Physical aspects of ageing
- (iv) Mental aspects of ageing
- (v) Problems for the elderly

Specialist Training Courses Available

Approx No who have
completed training

AIDS	Figures not available
Children and Families	Figures not available
Dementia Sufferers	25%
Older People	45%
Alcohol Abuse	8%
Disability	25%

There are a limited number of course places available and attendance is voluntary. There was no other staff development programme available.

Supervision Arrangements

Supervision was informal and ad-hoc; home helps could phone or call into the office or the assistant organiser would occasionally see a home help during a visit to a client's home. The Home Care Team were looking for premises in each patch with a view to introducing group supervision and improved support for home helps.

3.2 SERVICE USERS

Total number of clients on 19.02.90 = 836

Table 2 : Clients by Age

	MALE		FEMALE		TOTAL
	Number	% of Total	Number	% of Total	Number
Age					
85+	37	15	209	85	246
75-84	89	23	298	77	387
65-74	32	25	97	75	129
Under 65	29	39	45	61	74

Figures were not available for the number of service users who have certain disabilities such as dementia, sensory handicap, severe or profound physical disabilities or learning difficulties.

Hours of service received (approximate figures):

Weekly -

More than 15 hours	=	3%
Between 11-14 hours	=	4%
Between 7-10 hours	=	14%
Between 5-6 hours	=	26%
Between 2-4 hours	=	52%
Less than 2 hours	=	1%

Those who receive less than two hours tend to be Sheltered Housing residents.

Number who received help: *

Between 9.00 am and 1.00 pm	=	815
Before 9.00 am	=	18
Between 1.00 pm and 5.00 pm	=	19
Between 5.00 pm and 8.00 pm	=	1
After 8.00 pm	=	0
At weekends	=	48

Number waiting for service = 0

* Some people receive service morning and afternoon

Priority System

Band A = The client is guaranteed a service. The service is essential to the client remaining at home. The home help is the only person available to do tasks on the days allocated.

Band B = The client receives a regular service but could cope if the service was temporarily reduced or suspended due to staff shortage.

Band C = Minimum service to prevent further deterioration. If necessary, the service could be withdrawn for a long period with no risk to the client.

Service users move up or down this band system when or if their needs change.

Current number of clients who are:

Band A = 26%

Band B = 59%

Band C = 15%

These figures are approximate and include some households where two people require support.

Written Information for Service Users

Prior to a service being given, clients receive the Social Work Department leaflet "Helping you at Home". No written information is given after a service has begun.

Review System

Criteria used to decide the frequency of review visits = feedback from home helps, informal carers or GP's.

The most common period of review is once a year.

Reviews were mainly carried out by the assistant organisers. No written statement is given to the client following a review and clients were not always given advance notice of the assistant organiser's intention of paying a review visit.

Complaints Procedure

If a client is unhappy with the service or has a complaint, a meeting is held which involves the client, the home help and the home care organiser or assistant organiser. Departmental procedures were not in use.

4. LISTENING TO SERVICE USERS

4.1 PROFILE OF SERVICE USERS SAMPLE

Thirty home help clients were interviewed between January-February 1990, ie:

- 6 elderly people 75+ living alone
- 6 very physically handicapped people
- 4 people with learning difficulties
- 3* couples where both partners were vulnerable
- 6 dementia sufferers
- 3 elderly people who had recently been bereaved

* In the case of two out of the three couples both partners were interviewed and are counted in the survey as two people.

Although the numbers of female and males interviewed for this survey are roughly similar in numbers (16 males; 14 males) there are in fact more females than males in the overall home help client population (see section 3.2).

The majority of people interviewed were elderly, only five were under 60 years of age and half of the sample were people aged 80 or over. This is felt to be an accurate reflection of the home help client population.

Age Breakdown of Service Users

Number	Age
5	under 60
3	60-69
7	70-79
9	80-89
4	90-99
2	over 100

All except the three couples were living alone, mainly in tenement blocks sometimes in second and top floor flats. Eighteen people were housebound, this included five frail elderly clients who chose to stay at home; two who attended day care and were unable to get out otherwise; one woman who was chronically ill; and ten older people with physical disabilities who only got out once to three times a year. Eleven people lived in ground floor accommodation but were unable to get out without assistance.

They had been receiving home help services for varying lengths of time:

Length of service	No of clients interviewed
Under 3 months	1
7 months	3
1 year - under 2 years	11
2 years - under 3 years	3
3-4 years	6
5-8 years	5
14 years	1
	—
Total	30
	—

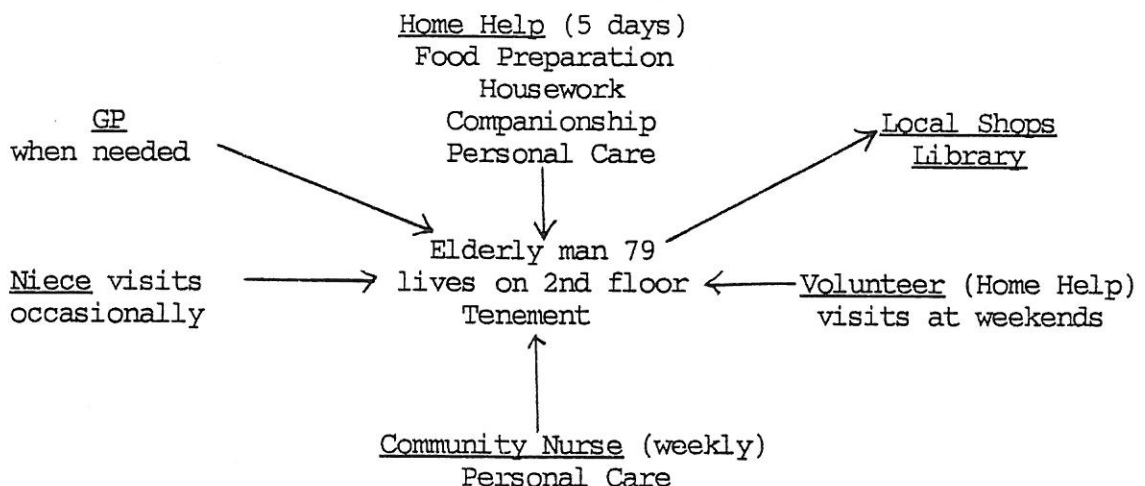
Eleven people were receiving a home help service seven days a week; eleven were receiving a five day service; six a three day service; and two only two days service. Of those receiving three days, two were physically handicapped, two suffering from dementia and an elderly couple. The two people receiving just two days were a physically handicapped man and an elderly man with learning difficulties.

4.2 CARING NETWORKS

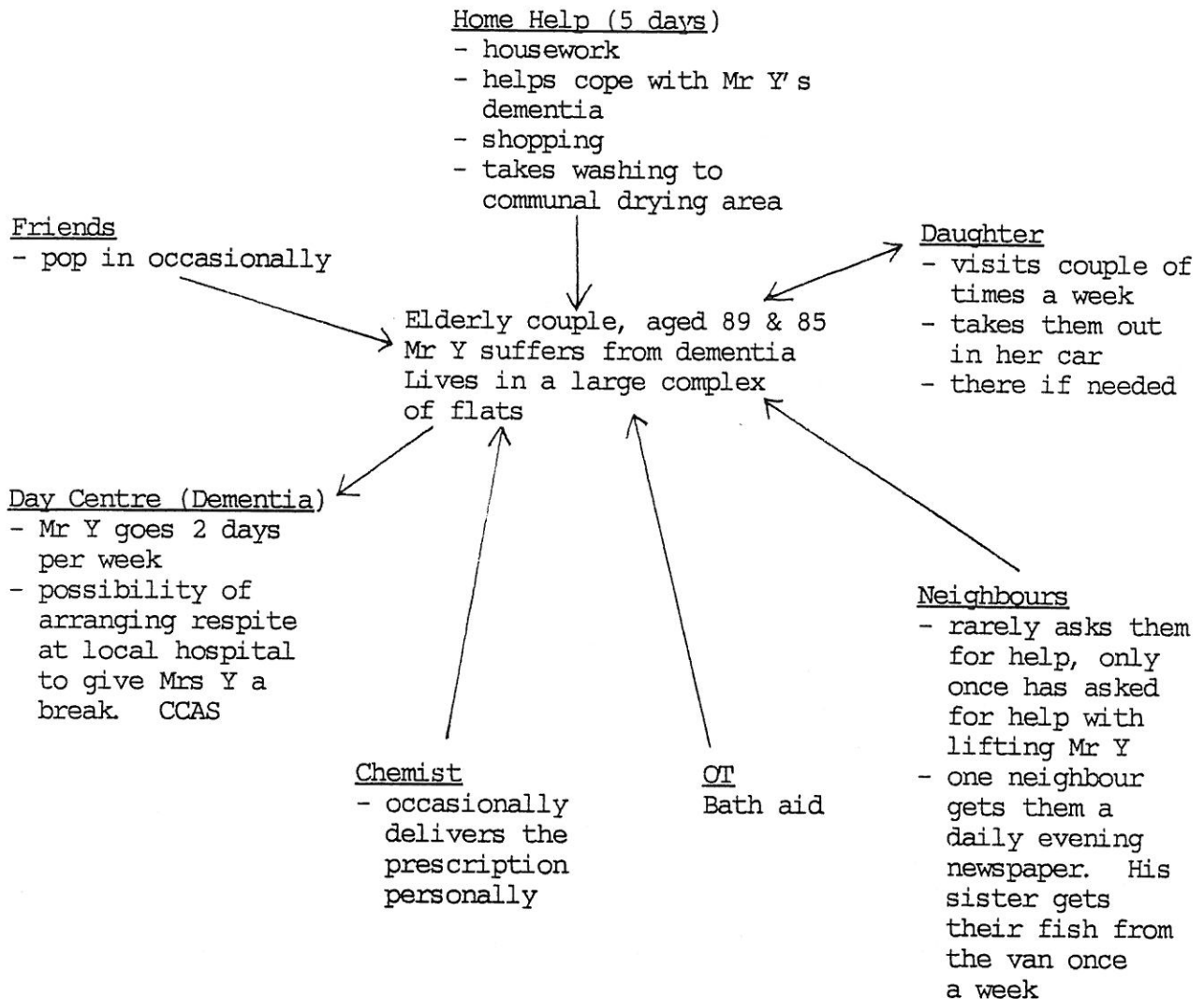
Informal interviews with Home Care users enabled us to map out a general picture of people's caring networks which included a range of formal and informal support. It was not the purpose of this research to rate the carers in terms of scale of importance. Also as the scope of the research was limited, the networks were not checked out with the formal or informal participants. This means that the results reflect individual perceptions only (some of which may or may not have reflected the full reality of the network).

As might be expected from the experience of previous studies (for example Addison, 1985, "A Report on Collaboration in Relation to Frail Elderly Clients") a range of caring networks emerged. These varied both in size and complexity combining formal support including social workers, home helps, GP's, community nurses, day care staff, and chiropodists with informal support from family, friends, neighbours, church members and local shop keepers.

One elderly man with learning difficulties living alone appeared to have a limited network with formal support dominating in the shape of the Home Care Service and community nursing. His only social contacts were visits to local shops and occasional visits from his niece. Nevertheless this man was not unhappy with his lifestyle and did not wish to participate more in the local community by attending clubs, etc. His home help was an important carer through his work role and by visiting at weekends on a voluntary basis.



In contrast the following diagram outlines the extensive network of one elderly couple combining formal support with several layers of informal support, ranging from the local chemist occasionally delivering prescriptions to concerned neighbours and regular family support:



4.3 COMMUNICATION WITHIN NETWORKS

Where there was interdisciplinary support (eg day hospital, community nurses, home help) there was evidence that services operated in isolation and were not always working together to meet people's changing needs. One elderly woman's experience was possibly the outcome of service providers not discussing her changing needs either with her, her informal carers or with each other. She attends a day hospital once a week.

"I look forward to going on a Friday, the nurses are very kind, you don't call them nurse, you call them by their names. I baked every week until recently, big sponges which I took to the hospital on a Friday. The sister said "Gran, you've not to bake any more, you're not able". I cried when they told me that, I've always baked".

As a result she has been limited in her activities at home and finds her days *"very long"*. The concerns of the day hospital staff for her personal safety whilst possibly justified, affected the action taken and did not take her views into account or seek to find alternative solutions which would have allowed her to continue with something she liked while minimising risks. For example, it could have been suggested to her that she considered baking cakes while her home help or another carer was present. This requires good liaison between the service providers and informal carers.

Through their daily contact home helps are in a unique position to develop knowledge of their client's daily routine and social networks. More than any other professional involved, they will be aware of changing needs and circumstances, for example increased frailty or a disrupted lifestyle following illness and to some extent they will also be aware of the needs and concerns of relatives, friends and neighbours who are providing support. However, it seemed to be the case that home helps rarely took or were possibly not encouraged to take the initiative to act on this information. This may be a reflection of the isolation of many home helps without adequate support and supervision.

One elderly woman had recently become housebound following a period in hospital. She had led an active life up until then and had attended a local church club. She expressly wished to get out more particularly *"once the weather improves"*. The home help was aware that her client had lost confidence to go out and suggested a possible solution would be for someone to contact her church club and find out if a volunteer would be willing to walk with her to and from the club. While this was seen as a possible solution the home help did not appear to perceive it as her role to try and re-establish this social link.

4. 4 CARE PACKAGES

All the people interviewed had what could loosely be described as "care packages". In some cases the range of support was extensive but no evidence emerged of any formal arrangement for the management of these packages of care.

The Assistant Home Care Organiser's initial assessment of need included assessment for other services such as day care, community laundry service, occupational therapy, meals on wheels and social work. Where support from both health and social services was required there was no evidence of joint planning or management of cases nor meeting with service users and their informal carers to discuss how best needs should be met. That is, other than "dementia liaison meetings" held at the area team which brought together professionals from Social Work, Day Care Hospitals and Community Health Services to discuss and plan for the needs of dementia sufferers and older people with mental health problems.

Where there was no dynamic assessment of people's needs or overall management of the care package, people were sometimes left to cope in intolerable circumstances. One elderly woman described how she had been caring for her severely disabled husband for several years but had now reached the point where *"I just cannot cope any more"*. Her husband has had several "strokes", has speech difficulties and suffered from incontinence. He was unable to assist in lifting himself in and out of his wheelchair or in getting in and out of bed.

They had daily support from a home help and community nurse although not necessarily at the times required. The nurse called at 11.00 am which, in their opinion, was *"too late"*, they depended on support from an ex-neighbour in the evening as neither service provided support at this time or through the night. They were both frail and consequently housebound with no family living in Edinburgh.

It was unclear why this couple's circumstances had been left to reach almost crisis point by the formal agencies involved although the situation had apparently been deteriorating for several years. Only recently had a social worker become involved. The situation had become so unmanageable for the woman that she had decided to ask for her husband to be cared for in hospital.

There were other examples of gaps in service provision particularly with frail elderly clients. Informal carers often provided vital support within "care packages" particularly in the evening and at weekends, if they were not available there was no support at all. One woman's home help present during an interview, expressed concerns about gaps in service and her client's safety due to her increasing physical and mental frailty. There were occasions when her informal carers were unable to visit which left her client in a vulnerable position. Another person, also elderly and housebound who depended on family support at weekends said: -

"I would like a home help at weekends, even just popping in".

The role of informal carers in providing vital support was borne out by this survey (see also section 5). As well as meeting a shortfall in formal services at times, their contribution as unpaid helpers was extremely valuable. However, their needs were rarely taken into account.

One carer, an elderly woman who was present during a client interview, was providing daily support to her brother who was housebound and caring for her husband who was blind. She expressed concern about her brother and worried in case he became ill and was unable to get help. The provision of a Community Care Alarm Scheme or CCAS could lessen her anxieties but at present her needs do not appear to be taken into account even though she is supporting two men with severe disabilities.

While the gaps in formal support are partly the outcome of a service predominantly available between 9.00 am and 1.00 pm other gaps appear to be the result of a narrow service focussed approach which often does not take into account potential contributions from the voluntary

sector and other agencies. One elderly housebound man said *"I would enjoy getting out occasionally for a few hours"*. He and his brother expressed interest in finding out about volunteers to assist but they did not know who to contact or how to go about achieving this. Another service user also elderly and housebound said *"I find my days long, I sometimes lie down in the afternoon for something to do"*. Her failing eyesight had severely restricted her participation in pastimes she previously enjoyed such as reading, knitting, shopping and attending a local club. She was unaware of resources and aids such as "talking books" or how she might be enabled to get out more.

4.5 DAILY ROUTINES

Amongst the people interviewed daily routines differed enormously. Several people led active lives with involvement outside the home, for example in part time work, as members of collective advocacy groups, attending college, visiting friends or relatives, attending day care and going to local pubs and clubs. Some very elderly people were content to spend most of their days at home being visited by friends or relatives or being occupied in some other way.

Nevertheless about eight older people who were housebound expressed feelings of monotony and boredom with their daily lives and expressed the wish to get out more.

"I knit from morning till night in between sleeping at times"

"I don't do much at the moment"

"I sleep a lot and watch TV"

"I sometimes do the housework before my home help arrives, for something to do"

The home help was frequently mentioned as an important person in the client's daily routines. Their presence and regular visits lessened feelings of boredom:

"She's a good laugh"

"He's a very nice bloke. He sits and blethers and passes the time"

"It is good to know someone is coming in each day, long may it continue"

"I get on well with my home help, she chats if she has time"

One woman who looked forward to having "a chat" with her home help had arranged for her niece to do her shopping so that the home help could spend more "chatting" time with her. The value of personal contact with the home help for many people was clear. Elderly dementia sufferers all referred to their home helps in ways that suggested friendship, affectionate relationships and at times a dependency on the home help:

"She keeps me right"

"I couldn't do without her"

"She's a grand lass"

One man who had great difficulty in expressing himself constantly referred affectionately to "that lass" during the interview and asked where she was.

4.6 FLEXIBLE SERVICES?

Research supports the view that most people given the opportunity, would prefer to remain at home rather than enter a residential home. (A Tinker, 1982, Staying at Home). However, for a couple of people with severe physical disabilities interviewed during this survey the reality of staying at home appeared very regimented with the person having to fit into professional's timetables. Domiciliary care for them meant being maintained solely within their home in isolation from their local community.

One woman aged sixty three with severe physical disabilities had an intensive package of care which excludes enabling her to get out. Her daily routine depended to a large extent on the time her helpers

arrived and she therefore had no choice in when to get up or go to bed. In the evening community nurses put her to bed sometime between 7.30 pm and 9.00 pm. Personal care was provided by district and community nurses, practical/domestic tasks were carried out by home helps. Her helpers did chat a bit but *"they did not have time for a cup of tea and a chat"* and *"the nurses are too busy to chat"*.

Research into residential care has shown that regimes organised to meet the needs of staff which deny residents choice and control over their daily lives is devaluing and leads to institutionalisation. It is now recognised that residential homes should be run to meet the needs of residents with regimes planned to meet their requirements, not those of staff. Choice and retaining independence are basic rights.

The lessons learned from residential care should be acknowledged by professional services when planning for the needs of people with profound disabilities. Community Care requires a value base which recognises basic rights with services and support, which enable rather than maintain, and is flexible to meet people's needs.

4.7 AN ENABLING ROLE FOR HOME HELPS?

The tasks undertaken by home helps identified by service users were strongly biased towards general housework tasks, doing the laundry, shopping and the preparation and cooking of food:

SUMMARY OF HOME HELP TASKS IDENTIFIED BY SERVICE USERS	NUMBER
General housework - eg hoovering, dusting, cleaning floors	23
Laundry - washing and/or drying of clothes	28
Preparation of food and/or cooking	15
Shopping	15
Collecting prescriptions, pensions and other "odd jobs"	6
Personal caring tasks - help with washing, dressing etc	4
Accompanying client on visit to shops, bank etc	4
Lighting coal fire	1

There were only a few examples where the home help instead of community/district nurse was involved in personal caring tasks. It was unclear whether or not clients had been given a choice of receiving this kind of help from a home help or a nurse.

Obviously home helps played an important enabling role in the lives of some of their clients through undertaking personal caring tasks and basic domestic/housework tasks. One young woman who was physically handicapped had stated to the home help organiser at her assessment visit that her preference was for a home help to assist with personal caring tasks as her situation did not merit medical attention:

"I discussed this with the home help organiser and she arranged for a home help to come in the mornings and the evenings. I can basically do most things myself but I need help with buttons and fastenings and it takes me longer to do it myself. It is very handy to have the home help in the evenings, especially if I'm going out".

The home help provided an extra pair of hands to speed up the process of getting ready to go out on those mornings the client worked at the community centre, preparing her meals, keeping the flat tidy and checking her appearance when she went out socialising. A special arrangement with the Home Care Service had been set up for another client who was physically handicapped which allowed his home help to undertake domestic tasks whilst he was attending college. The practical tasks performed were vital in supporting him to live an independent life.

Similarly, a couple both with learning difficulties had found their home help flexible in meeting their needs. Arriving at 9.00 am the home help did the housework, washing and preparation of food; basic domestic tasks which were difficult but necessary for the couple to perform. They had received extra home help hours to provide needed assistance with the preparations required for their holiday, in particular, help with ironing. Coupled with the help received from paid "neighbours" from the housing scheme the home help undertook the necessary practical support tasks to enable them to live an

independent life in the community. Practical domestic tasks were also an important service for many elderly people who would otherwise deteriorate more rapidly to a situation where more intensive support or even residential placement was needed.

There was one example of a home help working constructively and imaginatively with a dementia sufferer, regularly leaving written instructions for the meals prepared, to act as a memory aid for her client. However, this was not the experience of another elderly woman with dementia who was living alone. In her opinion "*getting my memory back*" would greatly improve her quality of life and there was clearly a need for those involved to assess whether this woman would benefit from the use of daily memory aids. She was very aware of her short and long term memory impairment and said she was "*very frustrated*" by it. Although the relationship between the woman and her home help seemed a close and valued one, the home help did not have the knowledge through training of practical ways to help dementia sufferers.

It was not always the case that the home help was working in partnership with the client or their informal carers. The home help of an elderly man with learning difficulties said "*He's not allowed to touch electrics, water or to cook. He flooded the flat downstairs once. He's told not to answer the door in the evenings*". His meals were provided by his elderly sister, who lived in another part of the city. The home help felt she did not have the time. Contrary to the policy aim of the Social Work Department this man was not being enabled through professional intervention to live an independent life in the community in a way that was appropriate to his age. The package of care he received did not reflect changing attitudes towards working with people with learning difficulties, nor had it been planned around his needs.

Only four people mentioned that they had been accompanied by their home help to local shops or to the bank and one home help present at the interview stated that she had been reported for sitting on a public bench whilst out walking with her client. Although the home help job outline for Lothian's Home Care staff clearly states that "following consultation with the Home Care Organiser the home help may

be asked to assist their clients in suitable leisure activities and to accompany socially isolated clients on visits outside their home.....", this did not appear to be viewed by clients or home helps as a legitimate task.

Service users were very hesitant about making demands of their home help which did not involve tangible practical tasks inside their home. One very elderly woman talked vividly about both her own and her husband's achievements at bowls and their love of the sport but stated that she could no longer enjoy this as she was unable to visit the local bowling green unaided. Her husband suffered from dementia and needed constant attention except on those mornings when he attended a day centre for dementia sufferers. Her home help thought accompanying Mrs X to the bowling green would be an unacceptable role:

"I think the home help organiser would have a fit if I took Mrs X to the bowling green".

It is possible that as half of the survey sample had been home help clients for between two and fourteen years, the majority would have been assessed for the kind of help they needed and allocated their home help when the tasks fell within a narrower range than those described in the relatively recent job outline (see appendix 1). Nevertheless, there is perhaps scope for development of the home help role so that people's needs are met in a more flexible way.

4.8 USERS' COMMENTS ABOUT THE HOME CARE SERVICE

"I think the home help service is excellent, especially for one on his own and disabled. It is good to know someone is coming in each day. It helps you on your way. It is greatly appreciated. Long may it continue".

(man aged 79, living alone)

"I find the home helps flexible and able to carry out the tasks I request"

(woman aged 65, living alone)

"I would never complain. I'm very very grateful for the help I receive. My home help is a good lass, she's very honest".
(woman, aged 102)

"I think the service should be more flexible, not for me but for elderly people - they have to have their main meal at lunch time. There should be more help for them in the evening".
(man, aged 23, with physical handicap)

"I am satisfied with the present service. I've had a couple of bad home helps in the past but I get on well with my present home help".
(woman, aged 87)

"I have a good laugh with my home help"
(woman, aged 93, amputee, living alone)

"I have a blether with her after she's finished her work".
(woman, aged 81, living alone)

"He's a very nice bloke. He'll go out of his way to get messages and things I didn't know home helps did. We're more like buddies.

"We've got too friendly and the housework has got less and less. When he's off the female home helps complain about having to do more".
(man, late 30's, physically handicapped)

"I prefer to have the same home help. I'm quite happy with the help we get as long as I am able to carry on as we are now"
(woman, late 80's, caring for husband with dementia)

"The help we get couldn't get any better, we're very pleased"
(couple with learning difficulties)

"I get on well with my home help. She chats if she's time. They're quite good as regards what they've got to do, some are better than others. If it wasn't for them I don't know how we (elderly people) would get on".

(woman, 80, housebound, living alone)

"The home help helps me to get ready in the mornings for my part time job. I would go daft if I stayed in the flat all day. It's handy to have the home help in the evening to help fasten buttons and make sure I'm looking alright when I'm going out, especially if I'm meeting a guy".

(woman, 24, physically handicapped)

"I'm very satisfied with the kind and amount of help I get. The home help is very friendly and helpful I wouldn't change a thing".

(woman, 60's, physically handicapped)

5. LISTENING TO CARERS

5.1 INTRODUCTION

Previous research has found that care in the community is primarily carried out by family members and more specifically by female family members. Parker's review of research on informal care (1985) and earlier reports by the Equal Opportunities Commission (1982) showed that female relatives "shoulder the main burden of responsibilities" in supporting people with disabilities of all ages. The General Household Survey of Informal Carers (1985) found that one adult in seven (14%) was providing informal care and that women were more likely to be carers than men although a substantial number of men were carers.

The findings from the sample of carers in this survey agree with previous findings. Of the nineteen carers identified thirteen were relatives, eleven of these female. Carers for the purpose of this survey were taken as relatives, friends or neighbours who were identified as playing an important role in the Home Care users informal network of support.

The Government's White Paper "Caring for People" 1989 which followed the Griffiths Report places an expectation on Social Services/Work Departments to consult with informal carers and to develop policies which take account of carers needs. The role of the Home Care Service in these future changes will be paramount. Supporting and listening to carers is an important, if sometimes forgotten, aspect of care in the community. Although only a small number of carers participated some of the issues which have been identified will clearly relate to the needs of all informal carers who are spending a substantial amount of time supporting a relative, friend or neighbour.

5.2 SUMMARY OF QUESTIONNAIRE FINDINGS

Of the ten carers who responded, seven were near relatives (four daughters, one mother, one brother and one niece) two were neighbours and one a close friend. One neighbour had sent a detailed letter explaining her experiences rather than completing a questionnaire - where possible the information supplied is included in the summary of findings. Another carer only completed part of the questionnaire as she felt some of the questions were no longer relevant to her situation since her daughter who has a physical disability was living independently.

Carers Ages (of those who gave this information)

Aged between:

35-40	=	2
46-50	=	3
66-70	=	1
71-75	=	1

The disability of the person carers supported

Disability	Number who provided support
Elderly with a physical disability	5
Elderly with mild confusion and physical disability	1
Elderly dementia sufferers	3
Young adult with physical disability	1

None of the carers lived in the same home as the person they supported, four lived in the same neighbourhood, five in other areas of Edinburgh and one carer lived in another town.

What support did they give?

For this question carers were asked to tick as many categories as applied. The response show the nine carers who completed this section all provided support in two or more ways.

Type of Support Given	Number who provide this
Personal Care	6
Friendship	5
Company	6
Advice	7
Shopping	6
Cooking	3
Housework	2
Financial	4
Getting Out	5
Phone Contact	7
Other (laundry)	1

One carer provided daily support, one visited twice a day seven days a week, three visited three times a week, two twice a week and two once a week. Three carers also added "and when needed". These carers have been providing support from between two years to ten years.

How did the carers feel about the level of support they gave?

Of those who provided comment, six carers felt the level of support they gave was adequate and two said they would like to visit more often. Distance was an obstacle for one carer and one elderly carer found her own frailty limiting. One said: -

"I look upon the care I give as a duty"
(niece supporting the elderly aunt)

another said:

"I find it very tiring at times, can drain me emotionally and finally doesn't leave me time for my husband or our own life"
(daughter supporting elderly chronically ill mother)

What did carers think of the present arrangements?

Five carers were satisfied but of these two raised concerns about future needs.

"My mother may need help to get my father to bed at night. I do not know who could provide this"

(daughter supporting elderly parents, father is a dementia sufferer)

"Although the present arrangements appear adequate I would foresee the need for increased care as my mother's mental capacity continues to decline and it would be helpful to know in advance what form it might be possible for this to take"

(daughter supporting mother who is a dementia sufferer)

Two carers would like changes in the present arrangements:

"It would be nice to have one night off or time off at weekends, as I would like time to myself"

(daughter providing daily support to chronically ill mother)

"Afternoon or evening visits would help to alleviate the long lonely days and nights that old people suffer, especially for those that only have three mornings a week from their home help. Also a better liaison between the different caring professions"

(niece supporting two elderly aunts)

What restrictions did carers experience?

Carers were asked if they experienced restrictions in any of the following ways and if they did to comment further - time off; breaks/ holidays; work; financial; social life; or other.

Four carers left this question blank and one said it was not applicable. Two had experienced restrictions in their working life:

"I do not have a job at present but would foresee that my ability to respond to any problems more or less instantly as I can just now, would be severely restricted when I return to work"

(daughter supporting mother - dementia sufferer)

Two carers experienced restrictions in their social life and one of them also experienced restrictions in time off, breaks and work.

"Holidays have been a problem as I would like to go away. Social life doesn't exist as I am usually too tired"

(daughter supporting mother)

One carer expressed general concerns about elderly people:

"Two weeks holidays or weekends away mean that the old people are left without my support. During the annual holiday it would be helpful if the old person could be given a holiday or special attention at this time"

(niece supporting two elderly aunts)

The links between carers and professional services

This section of the questionnaire asked carers whether they thought some of the support they presently gave should be provided by paid services, for example, Home Care Services or community nurses.

Four said they did not think any of the support they gave should be provided by paid carers and five thought some of the support should be. Of the latter two wanted support in the evening/during the night and four wanted more support at weekends. One carer identified a gap in support for wheelchair users:

"My aunt is disabled and in a wheelchair but Stockbridge Community Service have informed me that they do not have a service whereby my aunt would be collected and returned home. It is about a hundred yards distance"

How often were carers consulted about the level of support they gave?

Two carers left this question blank, five carers had never been consulted and two had although not in an extensive way.

"Only general conversation with a nurse"

"Initial consultation"

"Never, at times I have complained about lack of support"

One single parent mother identified in Home Care records as the carer of an elderly neighbour had sent a letter explaining that professionals had just assumed she would take on the role of carer which, given her present family circumstances, was completely unrealistic.

"On discharge from hospital it was assumed that I would be available to stay at home and nurse a frail old lady. I rang your Department (Social Work) and was told nothing could be done immediately. I was shocked to discover that at this critical time in her life there was no-one available to see her through the transition from the total dependence of the hospital situation back to independence at home"

Who in the Home Care Services do carers discuss any concerns with?

Two carers would contact the Home Care Organiser, three would discuss concerns with the home help or the Home Care Organiser and two would speak to home helps. One carer offered no comment.

Were carers satisfied with current arrangements?

Six carers said they were satisfied with the present arrangements with Home Care other than the need for a more flexible service as previously stated. One carer made no comment and two carers said they were not satisfied; asked what changes they would like to see they said:

"It would be nice to know that when things get too bad, extra help would be available"

"I think what is needed is an overall standard of training in house-wifery and cooking and not least an insight into the mental and physical needs of the elderly"

What support and information do carers need?

Carers were asked to tick as many categories as applied to them.

Support and Information	Number of Carers who would benefit
Practical help	2
Opportunity for a break	1
Someone to talk to	1
Information on services available	4
Information Carers Groups/Organisations	2
Welfare Rights/financial advice	2
Consultation with the Home Help Service	4
Advice on day-to-day caring skills (eg coping with confused behaviour)	3
Other (please specify)	0

Of the six carers who responded all felt one or more of these services would be of benefit. The most common needs were for information on available services and for consultation with the home help service, followed by advice on day-to-day caring skills.

What suggestions or comments did carers offer on how the present Home Care Services could be more responsive to carers and users of the service?

The comments from the six carers who completed this section were:

"I appreciate having one 'settled' home help who has become familiar with the needs of my mother and father. If it were not for the home help service my father could not have remained happily at home as long as he has done"
(daughter supporting elderly parents)

"As far as my brother's situation is concerned the Home Care Service is very good and apart from an additional visit as suggested I cannot see how it can be improved"
(supporting brother who is housebound)

"One of the biggest problems of the elderly who live on their own is loneliness and the feeling of dejection. It would be very beneficial to them if they could be integrated into the community"
(niece supporting two elderly aunts)

"I think more communication is necessary. The carer has to be helped, not just the person being cared for because what would happen if the carer just gets fed up. I think the carer is ignored to a certain extent as everyone knows we still carry on no matter what"
(daughter supporting mother who is chronically ill)

"I am very satisfied with the care and support given to me by the Home Care Service. My mother and I are very dependent on their help and both she and I would not cope without it"
 (daughter supporting elderly mother who is a dementia sufferer)

"I feel there is a need for a service to assist people in arranging minor household repairs. Possibly the home help could report anything required where the person is housebound"

(friend supporting elderly woman who is housebound)

5.3 KEY ISSUES IDENTIFIED FROM THE CARERS RESPONSE

From the carers comments and suggestions there are several key points relevant to the Home Care Service which offer some direction on how the present service could change to be more responsive to carers"

- *A more flexible service is required*
- *Consultation with the carers*
- *Advice on day-to-day caring skills*
- *Information on other services/resources available*
- *Reviews - planning for changing/future needs*
- *Respite care/sitting services*
- *Improved liaison between services and carers*
- *More support for carers*

The majority of carers found the Home Care Service invaluable but the survey findings also suggest that the present service is planned around the needs of the individual who requires home help support in isolation of their informal carers. As a result carers needs are being met (or not in some cases) as a 'spin-off' of service provision rather than through an explicit policy which takes carers needs (where appropriate) into account when help is being planned.

The idea of 'Share the Care' has been around for some years which recognises that informal carers are the backbone of community care. The Kings Fund informal caring programme in consultation with the Carers National Association and other voluntary groups has produced a '10 point plan for carers' which in their words

"provides a clear statement of what needs to be done so that carers - and the people they care for - can lead full and independent lives".

The plan is based on the recognition that services need to be planned for and with carers. Several of the points are reflected in this survey's findings"

"10 POINT PLAN FOR CARERS"

- 1 Recognition of their contribution and of their own needs as individuals in their own right.
- 2 Services tailored to their individual circumstances, needs and views, through discussions at the time help is being planned.
- 3 Services which reflect an awareness of differing racial, cultural and religious backgrounds and values, equally accessible to carers of every race and ethnic origin.
- 4 Opportunities for a break, both for short spells (an afternoon) and for longer periods (a week or more), to relax and have time to themselves.
- 5 Practical help to lighten the tasks of caring, including domestic help, home adaptations, incontinence services and help with transport.
- 6 Someone to talk to about their own emotional needs, at the outset of caring, while they are caring and when the caring task is over.

- 7 Information about available benefits and services as well as how to cope with the particular condition of the person cared for.
- 8 An income which covers the cost of caring and which does not preclude carers taking employment or sharing care with other people.
- 9 Opportunities to explore alternatives to family care both for the immediate and long-term future.
- 10 Services designed through consultation with carers, at all levels of policy planning.

6. CONCLUSIONS :

ASPIRATIONS INTO REALITY

The Government's White Paper, 1989, "Caring for People" (Para 1.11) includes amongst its key objectives for Community Care:

- to promote the development of domiciliary, day and respite services to enable people to live in their own homes whenever feasible and sensible;
 - to ensure that service providers make practical support for carers a high priority. Assessment of care needs should always take account of the needs of caring family, friends and neighbours;
 - to make proper assessment of need and good case management the cornerstone of high quality care. Packages of care should then be designed in line with individual needs and preferences.
-

6.1 THE GOVERNMENT WHITE PAPER AND NETWORKS OF CARE

Packages of Care - This research, by focussing on networks of care, has collected information on care packages and the service users' views of the contribution made by Lothians Home Care Service. The findings relate to a small sample of clients in one area team but nevertheless raise interesting issues for discussion in relation to the development of the Region's Home Care Service.

Looking at daily routines and establishing both the formal and informal support people had to help them remain at home highlighted the key role of family, friends and neighbours (see section 4.2); uncovered gaps in service provision; and showed that although care packages already exist they were not managed or reviewed in any formal way (see section 4.4).

Home helps were an important element of the caring networks but their role was often limited to practical housework tasks and the amount of time spent on personal caring tasks and accompanying clients outside their home was minimal (see section 4.7).

The majority of people had good relationships with their home helps and clients were generally appreciative of the service received. However, although in a unique position to have knowledge of clients' changing needs and to identify new needs, home helps rarely took the initiative to link with other carers (formal and informal). This could be partly explained by the isolated way home helps worked, the lack of formal supervision and few training opportunities (see section 3). The need for sensitivity and flexibility will demand more, not less, professionalism and skills in establishing service objectives and planning the allocation of resources.

"The home care service is a service where the outcome is almost totally dependent on the individual decisions - often made within the user's own home - which individual home care workers make. These decisions are not of a kind to be reviewed, on an individual basis, by even middle managers. To achieve change in such a situation we must give thoughtful, purposeful and sustained support to the workers who deliver the service and who shape its quality."
(Institute of Gerontology/Age Concern, 1989, "Achieving Change in Home Care Services")

Some intensive care packages served to institutionalise people within their own four walls (see section 4.6). Services were organised to fit professionals' timetables rather than around the service user. Good Community Care will require a value base that recognises basic rights with services and support which enables rather than maintains, and is flexible to meet people's needs.

Informal Carers - Services were planned in isolation from informal carers, who were sometimes coping in intolerable circumstances (see sections 4.4 and 5). A range of informal and voluntary provision including help from family, friends and neighbours, sitter services and volunteers is essential to supplement Home Care and to make best use of trained workers if Home Care is to meet the challenges it will face in the next decade and beyond. CPA drew attention to this interdependency as long ago as 1982:

"The proper role of the home help is to intermesh with such care (informal care) and not to replace it. "Support the Supporters" is not an empty phrase but a vital aspect of service provision".

(Rodney Hedley, Alison Norman, CPA 1982 - "Home Help - Key Issues in Service Provision")

Carers who responded to our questionnaire highlighted the need for: -

- a more flexible service
- consultation with carers
- advice on day to day skills
- information on services
- reviews and planning for future needs
- respite and sitter services
- more support for carers

(see section 5)

6.2 FUTURE DEVELOPMENTS - A CHANGING ROLE FOR HOME HELPS?

The context in which local authorities provide a home help service is changing rapidly. Demographic trends present new challenges: in particular the projected rise in the number of elderly people aged over 75 and those suffering dementia combined with a middle aged generation of carers who either do not exist or are unable to give intensive care. Developments in Community Care, not least the Government's Community Care Bill, will present challenges for housing,

Home Care, health, day and respite services for elderly people and those with mental health problems and learning difficulties.

The increased dependency of those referred for a home help service will more than likely result in a qualitatively different pattern of demand for services, for example, a greater demand for personal care and a more flexible service including evening and weekends. A main preoccupation of service planners will, no doubt, be how best to provide a more intensive service for very vulnerable people in the community whilst maintaining the main service to prevent premature admissions to residential care.

Current demands on the Home Care service and the vast amount of records that have to be kept mean that client reviews only happen infrequently, if at all. The Home Care Service could offer a more intensive service but only given adequate financial investment in the service, support for those in charge to enable them to take risks, clear objectives for the service and knowledge of how resources are being used. If the present service is expected to change in line with the Government White Paper without an input of resources, there will undoubtedly be problems.

Home helps have a lot to offer for example, in terms of support for people with dementia and their carers but they need specialist training and supervision. In addition the Social Work Department, in conjunction with Health and Voluntary agencies, needs to develop back up services such as sitter services and respite care. Skilled provision is only possible if skills are adequately taught. CPA predicted: -

"We are in danger of acquiring a new kind of intensive home care worker without clear concepts of the training she needs and the responsibilities which she should carry or what her status should be and this vagueness is not good for the worker, the client or the service".

(Hedley and Norman, 1982)

6.3 LISTENING TO SERVICE USERS

What were their aspirations for the future and a better quality of life?

"I would like to get out occasionally".

(retired widower, physically disabled)

"I would like to have a period when I feel physically better but my doctor says that with my heart condition and arthritis I will not feel much better".

"I would like to have a day without pain".

(elderly woman, recently bereaved)

"Getting my memory back".

(elderly woman with dementia)

"I find living alone very difficult. My mind is not on things at the moment".

(elderly man, recently bereaved)

"That's what vexes me, that I canna walk. If I could I'd be up that road like a linty! I need two arms to hang on to".

(elderly woman, 102 years)

"Two things I'd like, ground floor accommodation and two artificial legs. I'd like to get out and about locally".

(elderly man, physically handicapped, living alone in a top floor flat)

"I would like improved chiropody. My GP told me my feet were worn out".

(elderly woman with dementia)

"A new pair of legs!".

(housebound elderly woman)

"I don't like having to sign a book every week and hand it over the counter, I'd like to get my self-employed business going. Life here is okay. What I really want in life I can't have".

(physically handicapped man, wheelchair user, in his 30's)

"To be young again and walk over the hills and mountains. We could do with a wee drop more money and our health although people who are wealthy are not always happy".

(elderly couple)

"I would like two new feet, my sight and to walk but at 90 you can't expect an awful lot, I've had my three scores and ten!".

(housebound elderly woman)

"Getting out more. My friend who takes me out isn't very fit herself and can only manage it every couple of months".

(elderly physically handicapped woman, wheelchair user)

7 CHECKLIST OF KEY ISSUES FOR THE HOME HELP SERVICE

FLEXIBLE SERVICES

Community care requires a value base which recognises basic rights with services and support, which enable rather than maintain, and is flexible to meet people's needs.

- Is the home help service available to meet individual requirements, ie available 24 hours, 7 days a week?
- Is the kind of service offered flexible and responsive to individual requirements?

ASSESSMENT

Assessment requires an approach which allows the person to define what services they need rather than the service dictating what is offered.

- Is assessment looked at within the context of the person's total situation including an understanding of their formal and informal support networks and the person's own assessment of needs?
- Does assessment for services take account of carers needs separately from the person requiring a direct service?
- Is assessment treated as a dynamic process recognising that people's needs change which implies regular reviews?
- Are assessments multi-disciplinary in nature encompassing the range of possible services or are separate assessments undertaken by different professionals?

CARE PACKAGES

Care packages need to acknowledge the key role of family, friends and neighbours and be organised flexibly around the needs of each person.

- Are packages of care co-ordinated and managed in any overall way or are different services offered in isolation.
- Is there a named key person for example, an Organiser or Assistant Home Care Organiser, Health Visitor, Social Worker, whose role it is to arrange and co-ordinate the overall care package and who is known to all service providers?
- What effort is being made to meet individual needs and preferences within care packages, for example, the Home Care Service being flexible over the times a service is given?

COMMUNICATION WITHIN NETWORKS

To avoid duplication and enable care packages to be tailored to meet individual needs there needs to be regular communication between service providers.

- Is there a mechanism to enable the different people involved in a care package ie the client, informal carers and professionals, to communicate with each other?

CONSULTATION

Service users should be consulted about the services being offered or provided with the aim of providing more user-orientated services.

- Does the Home Care Service regularly consult service users and informal carers through surveys, group meetings etc about their views?
- How are the views of service users and informal carers incorporated by Home Care Teams into changes in policy and practice?

HOME HELPS

Home helps are an important element of the caring network and their contribution as such should be valued and enhanced.

- What efforts have been made to improve the support and supervision of home helps?
- Has the key role of home helps in community care been recognised and fully utilised by the Social Work Department?
- Do current training opportunities both in terms of quantity and the range of courses available meet home helps needs to improve and enhance their skills?
- Have the practical and training implications of an extended role for home helps as home carers been considered by the Authority?

ORGANISATION AND MANAGEMENT

The management of Home Care creates the environment which can either support or hinder the development of a more flexible and user-orientated service.

- Are Home Care Organisers and Assistants encouraging and supporting front line staff in taking a broader view of their role eg enabling clients to get out more?
- What steps are being taken by Organisers and Assistant Organisers to develop improved methods of providing regular support and supervision to home helps, for example, group supervision on a locality basis?
- What steps have been taken by Home Help Teams to improve information systems to enable them to effectively deploy scarce resources and to plan for future needs? Do they, for example, have good information on the staff resource ie their skills and training and comprehensive client information ie age, type of disability, housing situation, hours of service received?

- Have Organisers or Senior Organisers considered ways in which they can deploy home helps to provide a more flexible service to clients?
- What steps have been taken to formalise the review procedures including re-assessing the workload of Organisers or Assistant Organisers to enable them to have the time to undertake review visits?
- Have Home Help Teams considered ways they can improve the information given to service users both prior and during a service?

SOCIAL WORK DEPARTMENT

The Home Care Service has to be recognised as the key service of Social Work Department community care provision.

- Is the planned financial investment in Home Care by the Social Work Department adequate to enable the service to meet the challenges and changing demands of the next decade and provide the kind of service described in the White Paper?
- Are Organisers or Senior Organisers given appropriate support from senior management to allow them to develop the service and to enable them to be innovative and creative which may involve taking risks?
- Is the Home Care Service committed to an equal opportunities policy through its staff recruitment and training procedures, in its criteria for the service and in access to and delivery of the service? Is the service available to those who share the same home as their informal carers? Is the service able to meet the needs of ethnic minority groups?

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