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Monica Pauline Smith

## CARING FOR CARERS: AN EVALUATION OF A DOMICILIARY RESPITE CARE SCHEME

### ABSTRACT

This thesis evaluates a domiciliary respite care scheme which supported the family carers of physically handicapped and frail elderly people living at home. It considers the context in which the scheme arose and gives thought to its organisational structure. The consumer perspective is central to the evaluation of the scheme. The supported families are described in terms of the needs of dependant and carer and the effect of the scheme in relieving the caring situation. Although the majority of carers wish to look after their dependants caring can have an adverse effect on the well being of carers, both physically and emotionally. The scheme which was funded by the Manpower Services Commission (MSC) offered support to families by providing part-time trained care helpers who cared for dependants allowing the family carer to have a break. Carers were referred by statutory caring agencies, voluntary bodies and self referred following press publicity. Eligibility criteria related to the carers' health and responsibilities together with the care requirements of the dependants and the availability of other help. Of 208 families referred, 159 (76%) were supported during the two year pilot project, receiving 2-20 hours respite care a week, free of charge and at times suiting the carer and dependant. The level of dependency of the disabled people was high (27% unable to perform dressing/undressing, toileting, feeding or walking unaided). Their ages ranged from 3-93 years and the ages of their carers from 21-92 years of age. The scheme was valued by families for the high standard of care provided and the flexibility of respite care which gave help when statutory services were not available. Families, however, sought continuity of service. This could not be provided with MSC funding and the effectiveness of the service to carers and dependants was reduced by the need to employ and train new staff annually.

C A R I N G   F O R   C A R E R S :

An Evaluation of a Domiciliary  
Respite Care Scheme

submitted by

MONICA PAULINE SMITH

to the

UNIVERSITY OF DURHAM  
Department of Sociology and  
Social Policy

as qualification for the  
DEGREE of MASTER of ARTS

OCTOBER 1988

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25 JAN 1990

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## Glossary of Terms

- Carer - Someone who has daily, unpaid, responsibility for the personal and domestic support of another person and whose life is substantially restricted by that responsibility. The term 'informal' or 'primary' carer is familiar in literature but will only occasionally be used in this work when distinguishing the role from that of 'formal' (paid) carers.
- Dependant - Someone whose physical and/or mental incapacity reduces mobility and/or self care and leaves them unable to live independently.
- Families - Used to describe the household in which caring was carried out regardless of composition.
- Care helpers - Employees of Durham Community Care whose visits to homes relieved the carer of all caring tasks.
- Respite - " A temporary cessation of labour, an interval of rest ... leisure; opportunity for doing something." (Shorter Oxford English Dictionary).
- Domiciliary
- Respite - Relief from caring responsibilities for the carer which involves the dependant remaining in, and being cared for, in his own home.

Respite Care - "Anything that gives respite which allows the carer to have an external life free from worry." (DHSS SW Development Group, 1983, P. 14).

Domiciliary

Respite Care - The care given to disabled people in their own homes by the care helpers.



ABBREVIATIONS USED

CP	Community Programme
MSC	Manpower Services Commission
GMBATU	General and Municipal Boilermakers and Allied Trades Union
HA	Health Authority
LA	Local Authority
SS	Social Services (Department)
DN	District Nurse
OT	Occupational Therapist
CPN	Community Psychiatric Nurse
HH	Home Help
MOW	Meals on Wheels
Part III	Local Authority Care for Elderly People

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## CHAPTER 1

### INTRODUCTION

Long term disability, failing health or sudden dramatic illness affects more than the individual sufferer. People who continue to live in their own homes although requiring help with daily self care, principally rely on their family to provide that essential help. For some time Government has expected that the care of those who cannot look after themselves should be provided by the people closest to them and where people have no immediate family a network of friends and neighbours may be expected to take over (DHSS 1981).

There have been factors affecting the rise in the number of dependent people, such as the extended life expectancy of severely handicapped people, and an increase in the numbers of the very old. This has occurred at a time when the potential pool of carers (Moroney 1976) has contracted with reduced family size and an increase in the proportion of economically active women. The Equal Opportunities Commission (EOC) argues that despite the imbalance between those needing care and those available to provide care, at a time of economic recession, the neighbourhood, particularly the family, will be expected to play a major role in policy makers'



provision for the elderly and handicapped:

"Hence it is likely that families will find themselves with a cruel conflict of demands which force them to assume a caring role."

(EOC 1982 p. 3)

If that role is assumed it can mean they have to come to terms with:

"Problems that would hardly be tolerable to most people, giving up work, forfeiting all social life, never leaving the house for more than an hour at a time."

(EOC 1980)

The home care needs of carers, male and female, are central to this study. There is evidence that statutory domiciliary services are more readily provided if the main carer is male (Hunt 1968, Charlesworth et al 1983). However, research over the past twenty years shows that where a disabled person cannot manage personal care or household chores the contribution to their care made by statutory health and social services departments is dwarfed by that of the family (Shanus et al 1968, Sainsbury 1970, Harris 1971, Hunt 1976, Rossiter and Wicks 1982, Borsay 1986) and the impact on personal care tasks from neighbours and extended kin is also minimal (Cartwright et al 1973, Wright 1986, Borsay 1986). This leads to the conclusion reached by Sainsbury (1970) that the burden of care rests usually on one family member because:

"... domiciliary services were not sufficiently developed to play a well defined supporting role where disabled people lived with families."

(Sainsbury 1970, p. 145-6)

Sainsbury's study of a sample of people on local authority disability registers highlighted gaps in services which experience revealed also occurred in Durham.

In a review of research on informal care, Parker (1985) notes that the views of carers, whether of the services they and the people they care for receive or of the services they would like to use have been given relatively little research attention. There is evidence however, that 'time off' from the 'daily grind' (Bayley 1973) of being a 'brunt bearer' (Cartwright et al 1973) is a valued form of relief for carers of the elderly (Nissel and Bonnerjea 1982) and of children who are handicapped (Wilkin 1979, Glendenning 1983). The Durham Community Care scheme aimed to provide that 'time off'.

Goldberg and Connelly (1982), in their review of recent evaluative research into care of the elderly, point out that the vast majority of studies in the area are of the descriptive kind. They argue for experimental studies to assess the beneficial effects or otherwise of caring activities. Smith and Cantley (1985) claim that there are considerable difficulties in presuming an experimental ideal in social research and suggest a pluralistic approach which will "say what the programme is". They consider that this applies particularly to a novel programme and concur with Goldberg and Connelly (1982) when they concede the need for background work which relates problems, solutions and outcomes to defined variables. The present study falls into the category of a descriptive evaluation. The scheme being described was set up by a wife caring for her husband who had multiple sclerosis. Its origin was in the 'felt' need of an individual and offered a unique opportunity to trace the development

of a community based and consumer oriented care initiative in which the writer, as a friend of the initiator, was involved from an early stage.

The scheme was named Durham Community Care by a voluntary committee happily only partly conscious of the paradox in such a nomenclature. An awareness of the debate about community care is central to any understanding of the scheme and its purpose. Abrams (1977) notes there is confusion surrounding the term and Walker (1986) points out that it is an amalgam of two terms laden with "ambiguity, idealistic values and connotations". This confusion will be explored.

### Presentation of the Thesis

Chapter 1 is in three parts. In the first part the aims and objectives of the study are set out. The second and third parts focus on the relevant literature. A discussion of the background climate to the scheme considers the meaning attributed to the phrase 'community care' and its place in social policy and is followed by a review which identifies carers and their experiences of caring.

Chapter 2 gives a brief and selective review of the availability of respite for carers at a local and national level. Chapter 3 provides an analysis of the Durham Community Care Scheme, usually referred to as "the scheme", and Chapter 4 describes the method used in the evaluation. Chapter 5 gives a picture of the scheme in operation, the sources of referrals and selection of families. Chapters 6-8 report the findings of the surveys of carers concerning the dynamics of caring and the support available to carers in

Durham. An evaluation of the respite service is given in Chapter 9. The conclusion and policy implications are given in Chapter 10.

#### AIMS AND OBJECTIVES OF THE STUDY

The study focuses on the provision of home based respite for those caring for very disabled people. Carers' needs may be summarised as: recognition of their work, information from a readily available source and help with their responsibilities (Clarke 1982, Oliver 1983, Hodder 1985, Webb et al 1987). Recognition in the form of financial support is urgent for many thousands of families. Recognition can also come from providing them with the opportunity to maintain social and work relationships open to those not confined 'behind closed doors'. Schemes which provide such opportunities are most acceptable to carers if they offer flexibility, reliability and a high standard of care (Bristow 1981, Lovelock 1981, Bonny 1984, Thompson 1986).

The scheme set up in Durham aimed to identify carers and to explore their needs. By offering a service which would focus on providing an opportunity for respite it aimed to improve the quality of life of carers and dependants and delay admission of disabled people to institutional care.

The carer who initiated the scheme with drive and imagination was responding to the lack of adequate respite provision in Durham. Public awareness of carers' needs has developed over the past few years not least because of occasional press coverage given to their spokesman.

"When personal problems rooted in the social structure are articulated, they become public issues and hold the potential for creating social change."

(Bogdan & Taylor 1982, p. 20)

As a carers' spokeswoman the initiator had articulated her needs both nationally (through the Association of Carers and on a Yorkshire TV programme) and locally, in an attempt to change the position of carers and enhance their wellbeing. Durham Community Care was a practical response to that goal. In evaluating the scheme the writer aimed to establish if carers in Durham shared the isolation and exhaustion of the initiator and would benefit from the proposed form of support. In this way the research answered Abram's (1977) call for studies which build in clients' own concepts of need as legitimate determinants of effective care and concentrate on the effectiveness of specific measures.

This thesis discusses Durham Community Care and considers the implications of domiciliary respite provision for the recipients and statutory agencies.

## LITERATURE REVIEW

### Community Care and Social Policy

The term 'community care' has enjoyed popularity at national and local level for some time. Walker (1982) points out that this popularity and durability is in no small part due to the confusion of objectives applied to the term which make it "all things to all politicians and policy makers". This confusion is partly the result



of using the same term for policy goals and means (Parker 1985). But in Walker's (1986) view policy makers altered the definition when applying it to the delivery of services. Abrams' suggests a convenient definition of community care is:

"... the provision of help, support and protection of others by lay members of society acting in everyday domestic and occupational settings".

(Abrams 1977, p. 78)

He adds in explanation of this narrow definition that it distinguishes community care from other forms of social care both in terms of agents of care and its 'typical milieu'. The 'requisitionship' of the term (Walker 1985) and its application to the delivery of services by professionals in post war policy enactment influenced social care throughout the 1950s, 1960s and 1970s.

The thirty years after the war saw community care as a popular theme for both major political parties. The attractiveness of the solution seemed to lie in two areas. The economic merits of reducing the numbers of people in institutions and the political advantage which may be gained from supporting a move to empty hospitals which were the subject of disturbing reports in the 1960s and 1970s (Townsend 1962, Morris 1969, Miller and Gwynne 1971). The concept of community care can, however, be traced to the turn of the century (Walker 1982) with moves to limit the span of treatment of patients with mental illness, and ensure support from hospital almoners to keep families together. The recommendations for appointments of people with social work skills to help patients and

families which first arose from the Royal Commission on Lunacy and Mental Disorder (1924-6) were not couched in community care phraseology until the 1954-7 Royal Commission on The Law Relating to Mental Illness and Mental Deficiency. The Commission urged the care of patients in their own homes or in small group homes and an increase in the responsibilities of local authorities in the mental health area. Community care at this point therefore equated with social care (Abrams 1977) and included residential care. It still covered a wide range of provision in the 1963 Blue Book 'Health and Welfare: The Development of Community Care':

"The first aim of the health and welfare services is to promote health and wellbeing and to forestall illness and disability by preventative measures. Where illness or disability nevertheless occurs their aim is to provide care in the community - at home, at centres, or where necessary, in residential accommodation - for all who do not require the type of treatment and care which can be given only in hospital".

(Ministry of Health 1963, paragraph 5, p. 2)

As Jones, Brown and Bradshaw (1983) point out, the emphasis on hospital care as identified by the Blue Book would be for actual care only and a range of facilities would be available outside hospital. A consultative paper, 'The Way Forward: Priorities in the Health and Social Services' (DHSS 1977), reiterated a broad definition of community care which covered residential and day care, hostels and domiciliary support provided by statutory bodies, voluntary bodies, commercial organisations, local community based self help groups or family and friends.

Whether community care included or excluded residential provision in a definition, the ambiguity about community care was compounded by the group under discussion. The Seebohm Committee (1968) regretted that the concept of community care excluded hospital treatment or residential care and then concentrated its discussion on domiciliary services as they related to the elderly. The report 'Better Services for the Mentally Handicapped' (DHSS 1971) categorically felt each handicapped person should live with his own family provided this "... does not impose an undue burden on them or him". It exhorted local authorities to improve domiciliary services at the same time as it argued for more resident places.

Parker (1985) notes that throughout the 1960s policies which involved hospital closures planned complementary development of services in the community. For example increasing primary health care services, sheltered housing and training centres in relation to the needs of the mentally ill and increasing the home help service, and home nursing service. The 1968 Health Service and Public Health Act obliged local authorities to provide an adequate home help service and laundry service and the 1970 Chronically Sick and Disabled Persons Act made previously permissive powers of local authorities mandatory in relation to providing practical assistance to disabled people. Despite these Acts, however, the increase in domiciliary provision was never adequate to meet the needs of all groups. Economic pressure to accommodate reduced budgets and operate with cost effectiveness at a time in the late 1970s when there was an increase in the needs of particular groups, such as the elderly, produced a shift in emphasis away from 'care in the community' to 'care by the community' (Bayley 1973).

The 1981 White Paper 'Growing Older' stated that:

"Whatever level of public expenditure proves practicable and however it is distributed, the primary source of support and care for elderly people are informal and voluntary. These spring from the personal ties of kinship, friendship and neighbourhood. They are irreplaceable. It is the role of public authorities to sustain, and where necessary, develop but never to displace such support and care. Care in the community must increasingly mean care by the community."

(DHSS 1981, paragraph 1.9, p.3)

The justification for indirect financial cuts to services in the community was the existence and availability of a large informal sector (Walker 1986). The evidence to the Social Services Committee 1980 included a contribution from the Secretary of State:

"When one is comparing where one can make savings one protects the Health Service because there is no alternative, whereas in personal social services there is a substantial possibility and, indeed, probability of continuing growth in the amount of voluntary care, of neighbourhood care, of self help."

(Social Services Committee 1980, HMSO)

The trend towards an emphasis on care by the informal sector was paralleled by a development in the provision of services away from the centralised system which followed the Seebohm report (1968), to more responsible locally based services. These services are aimed at sharing more fully with "citizens" the "satisfactions and burdens of providing social care" (Barclay 1982) and fit neatly into the current political emphasis on the importance of family as a social unit.

The introduction of the role of voluntary services, concepts of neighbourhood care and self help also identify a further dimension to the community care debate, namely the geographical definition of the area in which communities care. The proximity as well as the willingness of relatives who can give practical assistance to elderly people is important in maintaining them in the community (Townsend 1957, Wade et al 1983). Similarly, the help offered by relatives to families with mentally handicapped members (Bayley 1973) is often dependent on location, although relatives may travel some distance to give support. Over three decades, which have seen a shift in emphasis from 'care in the community' to 'care by the community', the definition of community has remained difficult to establish. Bell and Newby (1971) refer to the work of Hillary (1955) who found 94 definitions of community, the only common element in them being people. They concluded that the term community often includes or implies a distinct territorial area. It is certain, however, that 'community' and 'community care' are warm and emotive terms (Titmuss 1968), which are politically attractive as 'good policy'. Durham Community Care recognised these sentiments extending the interpretation to home-based care.

The term community care is so value-laden that at least one feminist writer has argued for its abolition (Wilson 1982). Her argument lies in the belief that women's true role in caring is hidden. It is a view echoed in terms of the financial exploitation of women carers (Land 1978, Nissel and Bonnerjea 1982, Finch, 1983) and the devaluing of their caring tasks, (Oliver 1983, Briggs 1983). Parker (1981) reappraised the word 'care' arguing for the more graphic 'tending' as an accurate reflection of the activity.

This is generally accepted as a way of focusing on the reality of care and returns the argument to an examination of the providers of tending services.

Leat (1986) noted a unanimity in the pronouncements of Norman Fowler as Secretary of State for Social Services in 1984 and David Ennals, his predecessor by eight years, who from politically opposite stances concurred over the value of neighbourhood support to families in the 'front line'. 'Neighbourhood' is clearly geographical, but 'neighbourhood care' is unreliable in delivering help with 'tending' (Abrams et al 1981), unless it is organised (Hatch 1980) and preferably paid (Abrams et al 1986). An examination of community care leads back to the family. Within the family, tending and caring, which are based on love and duty (Finch and Groves 1983), are combined. The relevance of the current study is that it focuses on how the formal non-statutory sector can support the family care givers.

#### The Identification of Carers and their Experience of Caring

There is no clear idea of the number of people caring for dependants in this country. Parker notes that:

"... our knowledge about the population of dependent people is patchy (but) our knowledge about the numbers and characteristics of those who are caring for these people and maintaining them in the community is even less reliable."

(Parker 1985, p. 13)

She suggests, at a conservative estimate, there are 1.3 million people caring for others who require help with daily activities and self care. The Equal Opportunities Commission puts the figure at 1.5 million (EOC 1982). Recently, Webb et al (1987), quoted a Labour Party publication which estimated twice this figure suggesting there are 3.25 million cases. In the absence of national studies of carers, the estimates have to be based on small scale investigations and extrapolated from larger surveys of handicapped people. The reliability of estimates of handicapped and dependent people varies with the age group being considered.

The next section of the literature review begins with reference to studies of different dependent groups and the inferences made about their carers' situations. This is followed by a discussion of the identity of carers, their experiences and their felt need for respite.

### Elderly dependants

The elderly population has been growing throughout this century. The increase in both absolute and proportionate terms is a reflection of improved health and welfare provision and advances in medical science which have contributed to a reduction in mortality.

Whereas the population of those over 65 years of age is increasing, the rise in the numbers of very old and projections for the future show a leap in the population of potentially very frail and dependent people. The numbers aged 65 years or more were expected to rise by 5.5% between 1983 and 1988 but those aged 75 years or

more by 10.6% and those aged 85 or more by 22%. In the long term the numbers aged 85 or more will double. In 1983 there were 620,000 people aged over 85 years. There will be an estimated 1,047,000 by 2001 and 1,230,000 people in this very old group by the year 2021 (Henwood and Wicks 1985).

Increasing frailty is inevitably associated with the old elderly population who, surviving beyond the capacity for independent existence (Isaacs 1981), make greater use of welfare services than other age groups (Moroney 1976).

Less than 5% of elderly people as a whole are admitted to hospital or residential care (15% of those 80 years and over are in institutions at any one time). The vast majority, therefore, remain in their own homes (Jolly 1987). Although as a population group there is an increase in the number of elderly living alone, 29.7% according to the 1981 census, the very old are likely to form households with others (General Household Survey 1980), as are those in need of special care. In a survey of the needs of people in their last year of life, Cartwright et al (1973) found that 91% of their sample were living at home and two fifths of these were living with a younger generation, usually children. The 1980 General Household Survey (GHS) found 12% of elderly people were unable to go out of doors unaided. Henwood and Wicks (1985) applied these figures to the 1981 census and concluded 600,000 were housebound and 160,000 were unable to get out of bed unaided. This high dependency involves carers whether resident or non-resident.



Two national surveys over the past twenty five years which examined the lives of elderly people living in the community reinforce the caring role of families, particularly in terms of illness. Firstly, Townsend and Wedderburn's 'Aged in the Welfare State' (1965) and Shanus et al 'Old People in Three Industrial Societies' (1968) used the same sample of 2,500 people. Secondly, a similar sized survey for the government was reported in Hunt's 'The Elderly at Home' (1978). Townsend and Wedderburn were looking at the need for an expansion of statutory services which they concluded was urgent, despite the important supportive role played by the children of the elderly during illness and Shanus et al compared the integration into society of the elderly in three different western countries, America, Britain and Denmark. They found 42% of the elderly in Britain sharing a household with at least one child, compared with 28% in America and 20% in Denmark, but in all three countries half of all those who had children had seen one in the twenty four hours before the interview. In Britain 60% of elderly reported receiving help from their children and 50% reported giving help. Hunt found that 50% of her later sample saw relatives outside the household every week and this contact incorporated practical help and shopping.

Local studies of the position of elderly people also highlight the caring role of family members, Sheldon's early study of elderly people in Wolverhampton observed that:

"Whether married, widowed or single, they live, wherever possible, under the influence of family ties."

(Sheldon 1948, p. 140-5)

Townsend's study 'The Family Life of Old People' (1957) reported the close contact with female relatives and the dominance of the grandmother. In illness and infirmity old people relied on their children, usually the daughter living closest, for personal and domestic help. A study of middle and working class families in South Wales (Rosser and Harris 1965) showed that where families were dispersed the proportion of elderly seeing their children remained high although the burden of caring for an infirm parent devolved onto one child, usually the nearest daughter. Tunstall (1966) found similar reliance on family (children and children-in-law) to mitigate isolation in old age.

The studies of the 1960s and 1970s describe close networks of family supporting elderly people. They also recognise in passing that the bulk of personal care is most frequently provided by one relative, almost always a female relative and usually a daughter. As the number of elderly as a proportion of the population has grown, misconceptions have arisen about the care this group receives from relatives, who are portrayed as neglectful. Abrams' studies reported in 1978 and 1980 found only 17% of those aged 75 and over and 15% of those 65-74 years were sharing households with their children. The availability or unavailability of children applied to frequency of contact with nearly three in four elderly parents seeing their children once a week, but at the other extreme one in four saw a child only once a month or less. Abrams argues that for a large minority of elderly, family members are not available and where they are "family bonds are sometimes so fragile as to be almost non-existent" (1980). He had found that 30% of people aged 75 years

and over had never had children and 7.5% had outlived them.

Levin et al (1983) researching the supporters of confused elderly persons found the mean age of carers to be 61 years. As the elderly live longer their children will themselves be over retirement age. If Abrams' argument that the number of lone elderly is likely to continue rising is correct there are consequent implications for government's community care policies (Henwood and Wicks 1984). But although the elderly are likely to remain independent for longer and wish to do so, feeling they should not expect their children to look after them (Tinker 1985), the 1980 GHS returns clearly show that the very old move to live with relatives. This may follow years of caring from a distance (Wilmott 1986). Greengross (1982) argues that caring by today's families is maintained for longer and more comprehensively than by previous generations. Clearly :

"As more elderly people live to a very old age it is inevitable, then, that a greater proportion of the next generation will become responsible for their care."

(Parker 1985, p. 27).

### Handicapped and disabled non-elderly adults and children

While a consequence of old age is often increased disability and dependency, there is a growth in the number of people under 65 years who have special needs. In a national survey Amelia Harris (1971) calculated 3% of the population over 16 years to be in need of help for their daily living. Townsend (1979) working at a similar time excluded children under ten years of age. Their estimates, extrapolated to 1985 figures by Parker (1985) suggest, nationally,

between 1.26 million (Harris) and 1.9 million (Townsend) non-elderly people require daily help.

Estimates of figures for children must be arrived at from local studies. Parker (1985) cites Baldwin and Glendenning (1981) who put the number of children with severe impairment at between 89,000 and 126,000 with a prevalence rate of 6.2 children per thousand population.

Improvements in medical science enable low weight babies to survive, often with disabilities. Treatment is prolonging the lives of severely handicapped children (Topliss 1975) and similarly, advances in drugs and surgery are extending the lives of people with chronic illnesses.

The emphasis on care in the community encourages the care of handicapped young people and children in their own homes. 'Better Services For The Mentally Handicapped' (DHSS 1971) estimated over 70% of children with severe mental handicaps were living with their families. Bayley (1973) showed, from his local study of all people with mental handicaps who were registered with Sheffield Mental Health Service in 1968, that there is a decline in the numbers cared for at home as the age of the handicapped person rises. This may be the inevitable consequence of elderly parents unable to continue supporting handicapped offspring but Tyne (1982) suggests that on closer examination the institutional career of mentally handicapped people shows a more complex pattern with an increase in short stay admissions and discharges to unknown destinations.

Some severely physically handicapped non-elderly people live alone. Harris (1971) calculated 10% of the more severely impaired lived alone but with considerable formal support to maintain their position in the community (Lovelock 1979, Borsay 1986). However, as local work on the discharge of patients from hospital shows, the majority live with families who provide often very substantial care (Blaxter 1976, Thompson and Haran 1984).

While the numbers of non-elderly and children with mental and physical handicap in the community is clearly difficult to establish, estimating the numbers of carers involved is complicated by the fact that while rarely is care shared in a family some carers may be responsible for more than one dependant (Finch and Groves 1983, Wright 1985).

### The carers

It is strongly argued that family care means female care (EOC 1982, Rossiter and Wicks 1982, Finch and Groves 1983, Walker 1983). The EOC (1980) found that 75% of carers of elderly and handicapped are women. The OPCS survey 'Women and Employment' (1984) found 15% of all women had caring responsibilities for sick and elderly dependants and the figure rose to 40% of those aged 40 years and over. (OPCS - Office of Population Censuses and Surveys).

The early studies of families, Sheldon (1948), Townsend (1957), for example, stressed the importance of family care and implied that the main provider is a female relative, although they did not pursue the implications of this observation other than by describing the

relationships in terms of reciprocity. They acknowledged that caring can result in strain but little attempt was made to explore the dynamics of care.

The expectation that women should care continues into recent literature. Cartwright (1973) found in 83% of cases one 'brunt bearer', three quarters of whom were women. Of the carers of mentally handicapped children Wilkin (1979) found that "the majority of mothers carried a very heavy burden with very little support". Glendenning (1983) also found mothers carrying most of the burden which was manageable only if the father was perceived to be willing to help.

Women then, are the main providers of primary care but it should not be assumed that men take no part in caring. Husbands who care for their disabled wives face the same physical, social and emotional pressure as women carers (Thompson 1987). Studies have revealed, however, that secondary care is invariably provided by women. It is provided by the 'most available' female relatives (Blaxter 1976), often grandmothers (Seed 1980). Despite support from secondary carers, it is usual that once a main carer has been identified other potential carers have a much reduced profile (Jones 1985, Wright 1985).

#### Factors affecting availability of women as carers

The predominance of female caring occurs against a background of trends which, it could be assumed, would make it increasingly

difficult for them to sustain such responsibilities. Four factors affect the availability of carers.

Firstly, there has been a decline in the number of people of both sexes remaining single (Social Trends OPCS 1987) which will affect the supply of potential carers. Townsend (1957) remarked on the caring role of unmarried children, noting that they often postponed a likely marriage because of their responsibility towards a parent. Nearly 30 years later Wright (1986), in her study of unmarried carers of elderly people, pays greater attention to this shrinking number. She interviewed 36 daughters and 22 sons who had remained unmarried and were looking after infirm parents. The carers whose median age was 53 years, received little or no help from extended kin or statutory services. She argues that:

"It was unjust that the burden of care fell so unevenly on one person simply because that person was unmarried. Care should be far more equitably shared with other family members, with other people in the community and with the State"

(Wright 1986, p. 182)

Secondly, the changes in the pattern of marriage may have an impact on people's capacity to care in the future. Divorce and re-marriage of one or both partners has risen from 15% to 34% of all marriages between 1961 and 1980 (Social Trends, OPCS 1985). In this reshuffle of partners commitment and availability to parents, step-parents and parents-in-law becomes clouded (Parker 1981). Divorce may free people to care for their parents (Wicks 1982), however, reduced financial circumstances may make seeking employment imperative, or

unemployed single parenthood make caring for another financially impossible.

Thirdly, the size of families is steadily dropping, (Social Trends, OPCS 1987) with the result that more elderly couples will have no immediate family to look after them; adult children being unable to sustain two (or more) sets of parents/step-parents and with no extended kin to provide social support.

Fourthly, the sharp rise in the participation of <sup>married</sup> women in the labour market; an increase from 16% of the total workforce in 1961 to 25% in 1981 (Social Trends, OPCS 1985) has seriously affected their ready availability as carers. This is particularly so as the largest increase is among women aged 45-59 years, (a rise in the proportion from 32.6% in 1961 to 61.8% in 1981). Despite these difficulties, however, as Wicks (1982) points out women in this age group are still carers and managing to maintain several roles. But this can only be done at some cost and there is now some research evidence that these costs are being recognised and that 'society' does not believe care should be provided by families without some support. Parker refers to studies by West et al (1983 and 1984) carried out in Scotland in which participants were asked to indicate what care arrangements would be most acceptable, in their view, for a number of different disability and age groups. She quotes their conclusion that there was a:

"... consensus for care arrangements which can be termed community based care - day care centres, day hospitals and notably in respect of elderly disability, sheltered housing".

(Parker 1985, p.24)



West et al (1983 and 1984), found respondents expressing selectivity depending on the disability of the dependant. Informal care was considered more appropriate for psychiatric cases, but for the confused elderly residential care received overwhelming support. The sex of the respondents influenced preferences in regard to the care of both the young mentally and physically handicapped and elderly with a physical disability. Women more often cited a preference for community based care options with a professional input. This reaction is important because it reflects the views of the group on whom most informal caring rests.

#### The experience of caring

The evidence of the experience of caring for severely dependent people in their own homes comes from small studies which have looked at a particular consequence of caring and have usually concentrated on a particular group of dependants. Such studies, over the past fifteen years have contributed enormously to the knowledge of carers' problems. These problems have also been graphically described in personal accounts (Cooper and Henderson eds. 1973, Flew 1980, Oliver 1983, Briggs 1985 and Brady 1986).

The experience of caring which emerges is often portrayed as a balance sheet in which the costs seriously outweigh the benefits and yet carers express a wish to continue to care (Finch and Groves 1983, Bonny 1984). The emotional bonds which tie carer and dependant are usually based on affection (Borsay 1986) but may be overlaid with feelings of obligation and duty stemming from the

cultural definition of 'caring' as being 'natural' for women (Graham 1983)

"It cannot be understood objectively and abstractly, but only as a subjective experience in which we are all, for better or worse, involved".

(Graham 1983, p. 28)

Graham argues that it is artificial to separate 'labour' and 'love' in the caring relationship as together they signify women's role in a 'male-dominated and capitalist order'. Whether or not a marxist-feminist 'solution' to such an analysis is sought it is undeniable that caring involves undervalued heavy physical work and costs to the carer and family, which are financial and emotional regardless of the sex or age of the carer.

The financial costs to the carer are difficult to quantify. Rimmer (1983) cites the work of Wright et al (1981) who conclude that caring for people in their own homes is cheaper than institutional care in public expenditure terms, but this is because the costs to the family carer are being ignored. These costs are of two types, the direct extra costs of heating, special diets and equipment necessary to keep a disabled child or adult comfortable (Tizard & Grad 1961, Baldwin 1976, 1985) and the opportunity costs of constraints on employment. Baldwin (1985) found that the direct extra cost was not a fixed amount but varied in a complicated way with family income, the impact being most adverse for low income families.

Nissel and Bonnerjea (1982) in a small scale study of carers of the elderly estimated lost earnings of those who gave up work as £4,500 per annum and Baldwin (1985) found mothers of handicapped children "worked on average four hours less and earned £7.10 a week less than women in the control (group)". The length of participation in paid employment (Cartwright et al 1973) is reduced by caring and the career prospects and type of activity restricted. Wright (1986) emphasises that women, regardless of class, expect and are expected to maintain men in an employment role recounting sons who said that rather than them lose work a married sister living in the district would take time off her job to care for a parent who became ill.

Employment can prove an emotional restorative to trapped mothers (Wilkin 1983) providing "the opportunity for a break in a monotonous domestic routine" (Glendinning 1983). But as disabled children reach adulthood opportunities for their mothers to work are reduced (Hirst 1984 cited by Parker 1985). Carers of adults who become disabled may experience sudden changes in their lives which make it impossible for them to continue working (Oliver 1983).

The physical cost to the carer is also difficult to quantify. It is certainly true that lifting heavy and heavily dependent people puts carers at risk of injury (Bonny 1984). But a broader connection between caring and ill health has also been documented by Bristow (1981), Bonny (1984) and Charlesworth et al (1984) among others. Charlesworth et al found 22% of a sample caring for elderly dependants considered their health had been worsened because of caring. Jones (1986) reported 25% of carers with this feeling. It

cannot be overlooked that, for the carers of elderly people, middle and old age may be taking its toll on their strength, as it will for ageing parents of handicapped children. The physical strain of caring will undoubtedly exacerbate carers' problems and any way of relieving some of the physical burden must be of help.

The emotional cost of caring is not amenable to simple measurements. People may react to apparently similar pressures in quite different ways and at different stages in the caring experience, and the expectations placed on them vary according to class and generation (Wright 1986). The feelings of carers as they report them are, therefore, important and should be addressed if schemes are to be evolved which will help them to continue caring if they wish to. There is evidence that the level of 'strain' carers experience influences the eventual admission of dependants to long term institutional care (Isaacs 1971, Sandford 1975, Levin et al 1983).

Jones (1986) also noted a connection between the 'strain' experienced by carers and the admission to institutional care of their dependants.

"The strongest predictor in terms of the carers' characteristics was their self reported stress at the first interview. There was a very consistent and significant association between the stress of the carers and ensuing institutionalisation of their dependants"

(Jones 1986, p. 73)

Jones' (1986) study based on a survey of 256 carers, whose dependants were over 70 years and registered with two general practices used a distress scale from the Social Behaviour Assessment

Schedule with ratings based on the subject's verbal response to standard questions and designed to assess the 'subjective burden' expressed by the carer in response to the objective problem of the elderly dependant. There was a very strong association between relationship and stress with daughters experiencing significantly more stress than spouses. The level of stress was strongly associated with the level of physical ability, faecal incontinence, urinary incontinence, night disturbance, loneliness of carers, reduced contact with friends and carers' desire for a break. Wade et al (1983) found similar problems for carers noting particularly behaviour difficulties of the elderly dependants and strain associated with lifting. Thompson (1986) in a report of a survey of carers in South Manchester found a different connection between the effect of caring and the relationship of carer and dependant.

"The emotional effects on the health of same generation carers, who were mainly wives, was found to be particularly high when the dependants were males".

(Thompson 1986, p. 44)

This group of carers were coping with the most heavily dependent people who were severely incontinent. Similar findings are reported by Lovelock (1981).

The problems of caring wives bound by 'in sickness and in health' involve them with role changes as well as the assumption of heavy physical care. Oliver (1983) draws attention to the fact that fit wives of disabled men also have to cope with being 'de-sexed' by a loss of sex life and then the loss of the ability to relate to other women's lives.

If relationship is an important variable in carers' experiences of stress, their perceived quality of life and independence is equally important. Recent work by Pahl and Quine (1987, reported in New Society 1988) shows that the stress suffered by mothers of mentally handicapped children is linked with multiple impairments and behaviour problems of the child, particularly when they are combined with social adversity.

Parker (1985) classifies variables which appeared to be related to malaise scores in the work of Bradshaw and Lawton (1976) as follows:

" - Stress ameliorators ... mothers being able to do paid work unrestrictedly when they wanted to; housing which was suitable to the child's needs; satisfaction with the amount of help received in caring for the child; the family being able to take a holiday.

- Stress exacerbators ... night attendance required by the children; the child's poor general health (measured by need to be a hospital in-patient); the child's hyperactivity; and the parents health.

- Attitudinal factors ... mothers feeling more restricted though being no less able to get out than other mothers".

(Parker 1985, p. 59)

#### 'Felt Need' for respite care

Most studies which have looked at carers have identified a considerable felt need for better respite care. Thompson (1986) found only about one fifth (12:67) of her respondents in South Manchester felt they had no need of respite care. Each of these carers was responsible for a person whose dependency level was lower than the average in the sample. None of the dependants suffered mental handicap or dementia and this fairly independent state

enabled four carers to go out to work. The bulk of carers wished to have a break from caring but the respite care provision in South Manchester did not meet their needs and so was not extensively used. Day care did not provide a full day's care for dependants. Carers who wished to work full time were unable to do so because of the unreliability of transport and the early return home of their relatives. The area was apparently quite well provided with day facilities at social service centres and aged person's homes, and at geriatric, psycho-geriatric and psychiatric units. Residential places for adult physically handicapped adults were available through the social services department as was short-term fostering for mentally handicapped children. Domiciliary provision included a voluntary sitting service, a Manpower Services Community Programme scheme and an embryonic 'home-care' service. The take up of these facilities was "very low". Ignorance of domiciliary services could have accounted for this but it was probable that the value of the services to carers was limited because of the use of untrained staff.

Thompson concluded that the isolation carers experience and the strain of heavy demands from dependants, leave them too exhausted to absorb information. They require early identification by a professional assigned for that purpose and to give them support. They also require a flexible home respite care scheme (endorsed by 87% of her sample) which offers "relief care by trained care attendants in the home and free of charge". Similar conclusions were drawn for example, by Bristow (1982), Oliver (1983) and Bonny (1984) and proved strong recommendations for the creation of Durham Community Care.

## CHAPTER 2

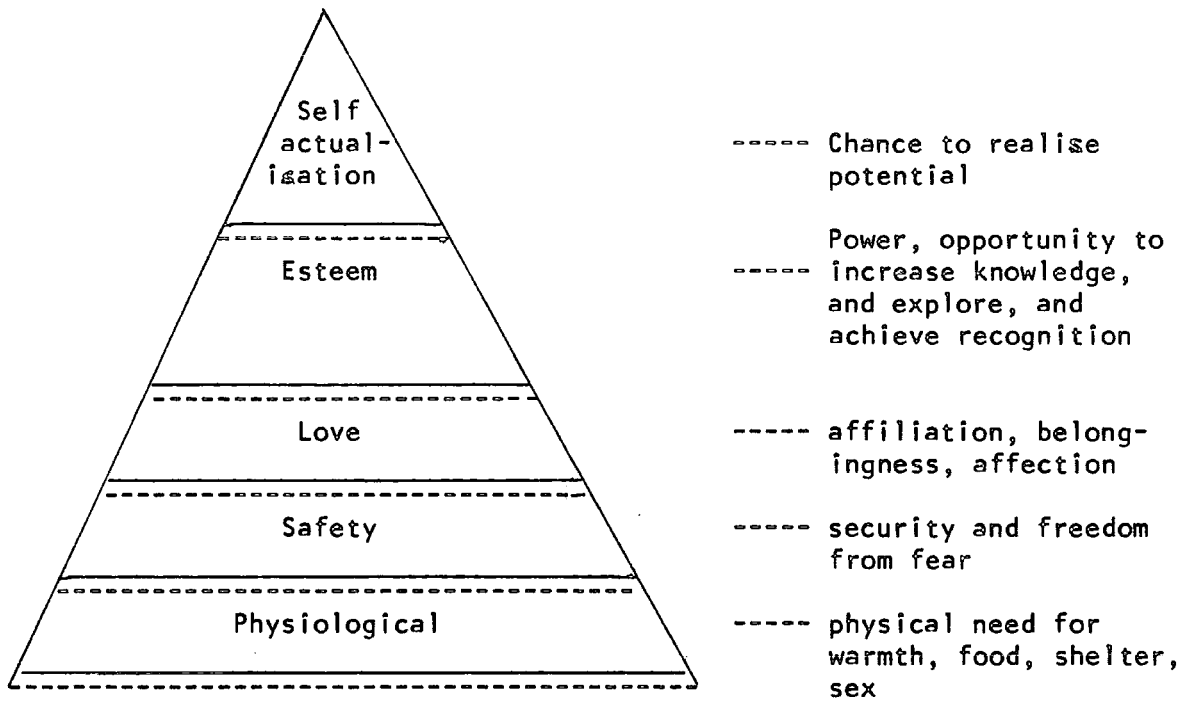
### RESPIRE CARE PROVISION - AN OVERVIEW

#### INTRODUCTION

This chapter reviews the forms of respite available to carers in general against criteria which are important to them when making care decisions concerning their dependants. It discusses the effect on carers of long-term care, and examines some community based care schemes. It considers these schemes against the triple criteria of: reliability; flexibility; and quality of care. There is some overlap between this chapter, and Chapter 8 which examines the formal support which was available to carers in Durham during the study, in particular to the families known to the scheme.

Carers' needs, as identified by their own representative body, The Association of Carers, are for recognition, information and help. Respite care can meet two of those needs, through helping to care for a dependant and responding to the carer's need for recognition as a 'worker', who is entitled to 'time-off' and as a person who has a right to try and realise her/his potential. Such needs correspond to the 'value' needs and 'cognitive' needs of Maslow's (1943) hierarchy of needs. These are the human needs which are the ultimate goal in personal development, possible only if physiological and safety needs are met.





From Maslow, A.H., Psychological Review, 1943

The definition of 'respite' used throughout this study is that in common usage, viz ... "a temporary cessation of labour, an interval of rest ... leisure; opportunity for doing something" (Shorter Oxford English Dictionary revised 1975). 'Respite care' is defined as "anything that gives respite which allows the carer to have an external life free from worry" (DHSS Social Work Development Group 1983, p. 14). The value of respite to carers will, therefore, depend on how effective it is in ensuring an external life free from worry and one in which they can increase their esteem and realise their potential.

It is argued that the successfulness of a provision depends on the extent to which Maslow's (1943) lower needs for physical care and safety are met for the dependant and how the human need for love and

approval are met for carer and dependant. The dependant must, therefore, be given a high standard of care in a comfortable and secure setting and the carer and dependant must feel that the alternative care provision is socially acceptable and does not damage the caring relationship or the relationship of either party with extended family or the wider community.

The starting point of respite provision by statutory and voluntary agencies has invariably been the dependant. This is probably inevitable when the care provided has to suit the needs of that person, particularly in meeting his/her physiological needs. The locus of care, its availability, reliability, flexibility and quality directly concerns the carer and these are the factors which determine the benefits gained. Figure 2.1 shows respite care provision by locus of care.

## RESIDENTIAL CARE

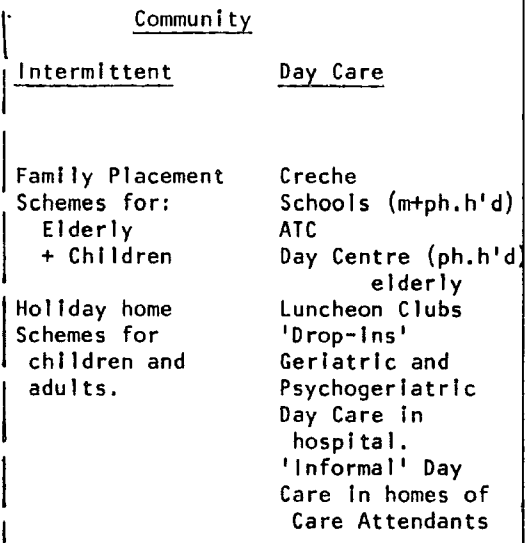
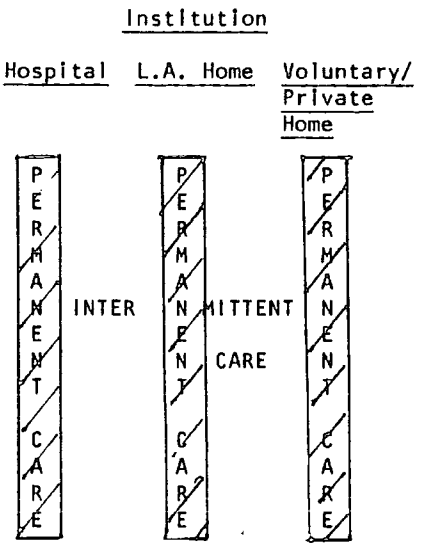
### Long Stay

Long term institutional care of over half of the non-elderly adults with a mental handicap continues to be provided in residential accommodation (HMSO 1971). But this is increasingly outside the hospital sector in voluntary and local authority homes (Social Trends OPCS 1985). Of the non-elderly with physical disabilities there is little information about numbers in institutional care but Parker (1985) concludes that "such care appears to play little part in the lives of the majority".

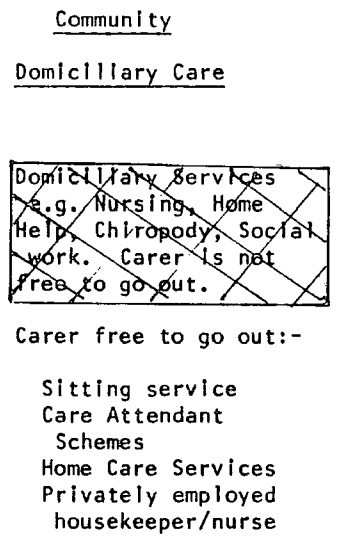
Figure 2.1

AN OVERVIEW OF RESPITE CARE PROVISION - BY PLACEMENT OF DISABLED PERSONS

DEPENDENT PERSON LEAVES OWN HOME



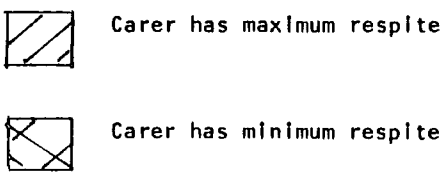
DEPENDENT PERSON STAYS IN OWN HOME



ORGANISATION AND FUNDING

H.A. Voluntary Sector/ Private Sector	L.A./	Voluntary Private Sector	H.A. L.A. Voluntary Sector funded privately, by L.A., L.A. + H.A. or combination	L.A. Social Services Education Dept. H.A. Voluntary Sector Independent or state aided Unfunded self-help	L.A. H.A. Vol. Sector, Independent or State aided Unfunded volunteer schemes. Private sector: housekeeper/ companion/nurse.
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- LA = Local Authority
- HA = Health Authority
- Vol. Sec. = Voluntary Sector
- m.h'd = mentally handicapped
- ph.h'd = physically handicapped



Despite the comparatively small scale of long term care provision, for many disabled, frail or confused people, it is the best or only option. The vast majority of dependent people, however, remain in their own homes and the support their carers receive and the care options available affect the numbers of people eventually admitted on a permanent basis to hospitals, local authority homes, or voluntary establishments.

Brody (1977) observed that admission to long term care occurs at different stages of needing services. Wade et al (1983), however, recognise that admission is often crisis based and the high degree of overlap in self care abilities of elderly in hospital, residential homes and sheltered housing suggests that care placement is not always related to care needs. They point to the considerable 'strain' experienced by relatives. The factors which caused carers to succumb to that 'strain' and influenced them ceasing to support elderly people at home included their own poor health and the low level of public sector domiciliary support. These factors are not entirely related to their dependant's disability level (Cresswell and Pasker 1972, Isaacs and Neville 1975) and suggest that earlier intervention and support for families may have enabled home based care to continue for longer (Wade et al 1983).

Once admitted to residential care the dependent person's relatives may continue to make very regular visits experiencing considerable disruption to their social lives (Harrisson and Ayton 1981, Wade et al 1983, Lewis and Meredith 1987); which can result in carer and dependant suffering depression (Owens 1987).

### Short Stay

The provision of places in hospital or residential homes for periods, usually up to two weeks, either on an annual basis or more frequently, is designed to give respite from caring and sometimes rehabilitation for the dependent person. It is provided primarily by the statutory authorities through referrals from doctors and social workers and is a planned service allowing carers to organise care some weeks or months in advance. The value of such respite is questioned by Allen (1983) who suggests that carers accept such arrangements when preferred alternatives are not available, for example long term care or increased support from the community, more day care or a package of domiciliary support.

### Reliability

In terms of the three criteria against which carers can measure their satisfaction with a respite provision residential and hospital care, both long term and short term, usually offers carers a reliable service. It is unlikely that an elderly person would be discharged, suddenly, from long term care although if his or her physical condition deteriorated he or she may be moved to a hospital where more appropriate care can be given.

The locus of care created anxiety for carers who were gaining respite from the short term admission of their dependant. The reliability of planned respite was lost if a relative had deteriorated to the point where he or she was no longer acceptable in a particular institution.

## Flexibility

Long term institutional care of relatives cannot offer flexibility to carers. It is not available on demand and visiting hours and geographical distance can make access difficult. These problems are faced also by carers using the service for their dependants on a short term basis. In a study of carers of elderly Jones (1986) considered that the hospital care for the most disabled in her sample and the inflexibility of short stay care made it unacceptable to carers. An EOC sponsored study found that the gender of the carer, discriminating against females, further reduced the service's accessibility and its use as a flexible provision for elderly dependants (Charlesworth et al 1984).

The need for short stay care which can be responsive to a crisis has been acknowledged by some health authorities in their services for families with handicapped children. For example Honeylands Family Support Unit in Exeter (DHSS 1983a) provides 'on demand' respite for several days at a time. Flexibility in provision therefore varies with the group of dependants being catered for.

## Quality of Care

Reports such as Townsend's 'The Last Refuge' (1962) were influential in raising public consciousness about the conditions in large institutions. Such general awareness alerts carers to the quality of care provided for their relatives and in the present study this aspect created most anxiety for carers who were facing care choices. People who had experience of statutory care questioned physical care

standards, loss of property and also staff attention to the personal and emotional needs of each resident. These anxieties led to guilt and regret expressed in several interviews denying carers an "external life free from worry" and mitigating against their acceptance of the respite provision (see p. 204).

## COMMUNITY BASED RESPITE CARE

### Short Stay Shared Care and Holidays

The statutory and voluntary sectors have responded to the values and ideals of 'normalisation' and 'integration' in their provision for the care of children with a mental handicap. Such views stress that exclusion from the rest of society of severely disabled children and adults by confining them in institutions is undesirable (Taylor 1981). The 'Normalisation Movement' (Blunden 1985) encourages "the use of culturally valued means in order to enable people to live culturally valued lives" (Wolfensberger 1980) and offers a general framework applicable to any handicapped or disadvantaged group such as the physically handicapped and elderly as well as the mentally handicapped (Williams 1985). Blunden (1985), when discussing the feasibility of normalisation, notes that it sensitises planners to the needs of individuals. The 'planners' have supported initiatives organised and funded by the health authority, local social services and the voluntary sector, the latter often jointly funded by statutory authorities such as foster care schemes for mentally and physically handicapped children which aim to meet individual needs. The Avon Short Stay Respite Care Scheme and the Durham Dr Barnado's Star Scheme are examples.

The same principles apply to schemes for elderly people such as those in Leicester, Calderdale (Halifax), Leeds and Liverpool. The aim of foster care or shared care, is to provide the carer with a break while their dependant is looked after in a domestic environment which resembles their own as closely as possible.

Holiday schemes run by voluntary organisations, churches and statutory bodies similarly provide carers with respite while dependants experience a change of environment, often away from their home area.

### Reliability

The organisation of shared care which is invariably provided by or supported by statutory organisations is a reliable source of respite for carers. Parents and relatives participate in guided and planned introduction to host families and arrangements rarely break down.

### Flexibility

Normally shared care on the model of foster care is planned in advance with relatives and host families. However the duration of the stay can vary from one night to up to a fortnight and the provision is geared to the needs of the disabled person within the host family thus providing flexibility in the care provided. The most serious limitation is the restriction on the level of disability of the child or elderly person. Multi-handicapped children are less acceptable to host families and Leat (1983), pointed out in a review of short stay foster care for the elderly that the client group was restricted to the least physically disabled and mentally infirm. Carers experiencing the most trying



aspects of care for the elderly, incontinence and confusion, were least likely to receive respite through this form of care.

### Quality of Care

The monitoring of foster care schemes is thorough. In the case of elderly clients Leat (1983) observed that the elderly themselves were happy with the arrangements although some carers expressed a feeling of inadequacy at the time of the first stay.

Children may have difficulty settling in new surroundings and the skills of the foster family and placement officers are needed to help them. Parents will not benefit from respite, regardless of the location of the child, if the separation is marred by worry (Wilkin 1979, Glendinning 1983).

### Day Care

The range of provision which falls under the category of day care is wider than any other community based system of respite for carers. The service may be funded by statutory or voluntary bodies or be an unfunded self help group. Unfunded schemes are often the response to locally identified need which a voluntary body or local authority may eventually support financially.

Schemes are invariably geared to a particular dependent group and focus primarily on their specific needs rather than the carers need for respite. Schools and Training Centres provide day time activity for

young physically and mentally handicapped people. Day care for the elderly is provided at hospitals, residential homes or day centres.

There are many innovative schemes run by local authority social service departments and health authorities which explore different forms of day care and have the dependent person as their primary focus.

The provision for non-elderly physically handicapped is restricted to day centres and the young chronic sick wards of hospitals.

### Reliability

Day care is not a reliable means of respite for carers. Schools are closed for holidays and hospitals lack space. Day care at a psycho-geriatric unit may be available only for a set period, of perhaps three months, for rehabilitation. Irregularities of transport may mean a dependant misses days or waits a long time for the lift by car or ambulance. The unreliability of day care presented particular problems for carers in Durham which are described in Chapter 8.

### Flexibility

Day care provided in statutory authority establishment is not usually available on demand. Slow processes of referral and assessment are compounded by waiting lists for vacancies. Care is dependant orientated, so little cognizance is made of the carer's need for respite, facilities invariably close mid-afternoon preventing a carer using the time to go out to a full-time job.

Provisions are geared to a particular level of incapacity and if a deterioration occurs in a disabled person's condition it is likely she/he will be excluded from a centre if the staff claim they are unable to cope with that person.

### Quality of Care

The quality of care provided is variable. Importantly, however, day care is often the only option available to families. Regardless of location, or dependent group it is a concept which is understood and accepted by people not involved. As such it therefore has credibility as a respite provision although its value for many carers is limited.

### DOMICILIARY BASED RESPITE CARE

Respite afforded to carers who are able to leave their relatives at home while they enjoy time to themselves involves the least disorganisation of family life.

### 'Crossroads' Type Schemes

Crossroads Care Attendant Schemes began as a response to the personal needs of a non-elderly physically handicapped man and his mother. From a pilot project in Rugby in 1974 the organisation now consists of over 100 affiliated but autonomous schemes operating throughout the country and abroad, providing relief to carers of dependants of all ages suffering severe physical disability or mental handicap.

Care attendants, paid an hourly wage in line with local authority care staff, come to the dependant's home at the times the carer most need relief and perform all the tasks the carer would normally have carried out (Bristow 1981). The tasks include getting up, putting to bed, 'daily living' tasks such as toileting and feeding, any necessary domestic tasks and general entertainment and supervision of the dependent person. Overnight stays can enable a carer to have uninterrupted sleep or a longer break.

Crossroads is a voluntary organisation but each scheme is substantially supported by joint or main health or social services budget funds. Similar schemes have been developed by social services departments and in Hampshire are now nearly county wide (Lovelock 1981). North Tyneside Social Services Department took over a Crossroads Scheme after 12 months of operation.

An independent registered charity, PRAMA, based in East Dorset also aims to support and 'complement' the work of carers. Like Crossroads schemes the care attendants are trained and work part-time. The funding is entirely from voluntary donations and raised from industry and commerce (DHSS 1984). Although people unable to pay for the service are supported free of charge PRAMA does ask client families for a donation. This same principle is followed by the Leonard Cheshire Family Support Schemes which support carers of non-elderly physically handicapped people. They are funded from statutory sources and privately raised donations. (PRAMA - Pain Relief and Management Association).

A third source of funding, the Manpower Services Commission (MSC), finances schemes such as the Cleveland Social Services Department's,

Neighbourhood Care Attendant Scheme and was used by Durham Community Care. As with Crossroads and most local authority schemes no charge is made to the families.

### Sitting Services

The service offered by 'sitting' schemes is essentially a way of providing an occasional few hours of respite through companionship rather than substitute care. The Hounslow and Spelthorne Health Authority and the Ealing Health and Social Services Scheme cooperates with Red Cross volunteers offering relief to carers of the elderly. Volunteers are also used by the Salford Health Authority joint funded sitting service for carers of mentally handicapped children and young people. The high demand from parents in Salford for the sitting service suggests, therefore, it provides a high level of practical care for very dependent children and is more than a sitting service. Families prefer it to the day care crèche facility incorporated in a full day and evening centre.

The voluntary sector is the primary provider of sitting schemes, often financed by MSC funds. Training and the accountability of staff are important for maintenance of the confidence of the user (Abrams et al 1981, Herbert 1983). Two examples illustrate the problems faced by the voluntary and the statutory sector in establishing a credible and useful scheme if using volunteer help. Age Concern Doncaster made steps to support carers of the elderly in 1982 with a volunteer scheme, the idea lacked credibility, in the eyes of statutory agencies, who did not refer families and the families, who in turn, were unwilling to accept a volunteer. The Alzheimer's Disease Society in South Cleveland

found relatives were reluctant to accept volunteers who offered domiciliary respite except under "really pressing conditions" (DHSS 1984).

Lessons learnt from such experiences lead to an acceptance of a restricted role for volunteers, a high input of training and supervision to establish the credibility of a scheme or the restriction of volunteers to those with, for example, nursing qualifications, thus utilising existing expertise.

Sitting services for parents of children with handicaps are being developed as extensions of self help groups and crêches. The Rainbow Clubs address this need and in Banbury the club is providing 'roving carers' who take over care of children in their own homes, enabling parents to go out in the evening.

Parker (1985) reports an unusual sitting service available in Rochdale. Sitters without nursing qualifications are employed by the social services department to provide overnight observation and care and are supervised by visits from the nursing service. This primarily offers carers the chance of a full nights sleep.

### Reliability

Three reviews of Crossroads schemes (Bristow 1981, 1986, Bristow and Brenig-Jones 1983) stress the importance of providing a service which can be relied upon by carers. Lovelock (1981) also stresses the carers' need to be able to plan confidently knowing an attendant would arrive at a certain time and provide care of an acceptable standard.

Reliability of domiciliary respite care is a management priority stressed by Leonard Cheshire schemes (personal communication) but cannot be guaranteed over time with MSC funded projects which are obliged to recruit new staff annually. There is no evidence from the literature that sitting services are any less reliable than any other form of domiciliary respite but the use of volunteers is perceived by carers to involve an inherent problem of uncertainty which militates against their use.

### Flexibility

The care attendant schemes described aim to provide a flexible service to the carers of all dependants (except the mentally ill), or a particular client group (Leonard Cheshire Schemes concentrate support to families caring for non-elderly physically handicapped). Within the funding limits management decides on the principles of substantial care hours to a few or fewer hours of respite to a larger number of families (Turnock/Northampton Health Authority, 1986). The respite cover available is totally flexible to the needs of the family in terms of time, duration and care support provided. MSC funded schemes have difficulty providing 24 hour cover because of the employment restrictions on overnight work although this was overcome in the early operation of Cleveland Neighbourhood Care Scheme (Van Loo 1984) and Durham Community Care.

Sitting services do not usually provide the flexibility of service which can offer a carer substitute care. Problems of accountability usually limit the role of volunteers to non-nursing tasks unless trained and working to a qualified organiser.

## Quality of Care

Care attendant schemes provide a service which is a separate entity but complementary to both the home help and nursing services (Dawson 1983). The quality of care however must be of a high standard for the families to feel confident in using it. Training of care attendants and their accountability to a supervisor encourage confidence from the users. This is recognised by sitting services which limit their schemes to what they can realistically offer. There is not, however, much evidence that that is what best meets carers' needs (Parker 1985).

## FUNDING AND ORGANISATION

The statutory sector is able to provide domiciliary care services on a county or district wide scale. The payment of care attendants or helpers (Davies 1985) on a neighbourhood basis or the funding of care attendant schemes provides protection for carers. Accountability and clear delineation of roles are a feature of statutory services which need not lead to inflexibility.

The voluntary sector may however be better able to respond to consumer demand, experiment and take risks. On a very small scale support groups can meet a specific local need and are free to publicly present a case and lobby politicians. The greater number and range of schemes occurring in the voluntary sector suggest carers' needs, including respite needs are being imaginatively addressed outside the statutory services. Figure 2.2 gives examples of the range of support which may be available to carers from the statutory and the voluntary sector.



Figure 2.2SUPPORT FOR CARERS AND THEIR DEPENDANTS\*STATUTORY SECTOR

Intensive domiciliary home care schemes  
 Care attendant schemes  
 Combined respite schemes - short stay  
 Family placements and resident carers  
 Home helps, meals on wheels  
 Occupational therapy, chiropody etc.  
 Social work  
 'MacMillan' nursing  
 Sitting services  
 Short stay care  
 Day care  
 Carer support groups  
 Transport  
 Luncheon clubs  
 'Special' schools  
 Training centres  
 Rehabilitation centres  
 Sheltered employment  
 Home alarm schemes  
 Mobile wardens

VOLUNTARY SECTORDomiciliary Services:

"Crossroads" type care attendant schemes  
 Care attendant schemes (others eg MSC funded)  
 Marie Curie nursing care  
 Home hospice care  
 Sitting services

Services for specific disability groups:

Day centres  
 Holiday provision  
 Clubs  
 Crèches  
 Schools  
 Rehabilitation centres  
 Sheltered employment centres

Carers support groups  
 Self help groups  
 Information services  
 Telephone helplines  
 Transport

\*Examples of the range of help available to carers, subject to family composition, dependants' disability and home locality.

Such support is subject to family composition, dependants' disability and home locality.

The evidence available shows that carers prefer their dependants to be cared for at home (Bristow 1981, 1986, Glendinning 1983, Wilkin 1983, Jones 1986) but the patchiness of provision and the variety of projects suggest that much more information is required before the relative benefits of respite care can be properly evaluated. Parker (1985) proposes that any evaluation of domiciliary care attendant schemes for one or more client groups (as suggested by Bristow and Brenig-Jones, 1983) should "be evaluated alongside adequate provision of statutory services". This seems to be an ideal difficult to attain with the pressure on existing domiciliary services unlikely in the near future to reduce the reliance on carers as a resource.

### CHAPTER 3

#### THE DURHAM COMMUNITY CARE SCHEME: ITS CREATION AND DEVELOPMENT

##### INTRODUCTION

In 1983, the initiator of the Durham Community Care Scheme wrote a proposal suggesting the setting up of an experimental pilot project to give assistance to people who had the daily care responsibilities for a dependent person. The aims comprised:

"Assessing the needs for and feasibility of a novel form of support for old, sick and mentally and physically handicapped people who wish to be cared for in their own homes."

(Brady 1983)

The project was to be funded initially by the Manpower Services Commission (MSC) in the hope that it would be accepted and developed by the county council at a later date.

This chapter begins by giving the background to and the creation of Durham Community Care. The initial proposal is set out in detail, examining the structure envisaged and the motivation for the idea.

This is followed by a discussion of the organisational planning of the scheme. The 'program planning model' (PPM) described by Van de Ven (1980), is used to trace the development of the proposal to what he terms the 'activation stage'. The discussion follows the development of the scheme during its first two years through an examination of three threads of concern in the study of organisations which Tichy (1980) describes as:

- a) the 'ideological and cultural mix' problem;
- b) the 'political allocation' problem;
- c) the 'technical design' problem.

These three areas, involving the values of an organisation, its distribution of power and financial generation and management, are not mutually exclusive but may produce problems of different intensity at different times.

The PPM has been used in this analysis because it is more useful than other models, either the biological analogy (Kimberley 1980) or the ecological approach (Penning 1980) in analysing the pre-activation stage of Durham Community Care.

The final section of the chapter describes the 'Activation' and 'Operation' stages of the scheme (Van de Ven and Koenig 1976). A marketing model is applied to the overlapping 'activation' and 'operation' stages which reflects the influences of the environment on the development of the scheme. The marketing model, developed by Kotler (1982) defines a 'public' in terms of people or organisations which influence another organisation. In applying these marketing

principles to non-profit making organisations such as welfare bodies. Kotler divides 'publics' into four groups reflecting the input into an organisation, its internal resources, intermediate enablers and consumers. The discussion considers the 'publics' to which Durham Community Care reacted and the utilisation made of the contacts and resources at the disposal of the committee.

### THE PROPOSAL FOR A RESPITE CARE SCHEME

The features of the Durham Community Care scheme were that it should be sufficiently flexible to:

- a) provide for people with any degree of disability;
- b) provide relatives with relief from caring when they found such relief necessary.

The sensitivity of the scheme to the care requirements of those receiving the service was to be ensured by their co-opted representation on the organising committee. Primary health care teams were expected to be the main referring agencies thus enabling contact at an early stage and hopefully preventing crises or family breakdown.

The Snowdon working party report 'Integrating the Disabled' (1976) considered that one of the immediate priorities for the severely disabled needing special care was consideration of the provision of Care Attendant Schemes on the model of Crossroads Care Attendant Schemes. Together with proposals on accommodation and co-ordination on housing and domiciliary services the report suggests that the ideals of handicapped people remaining in their own homes could be made more

attainable. In the view of the report's authors "the most important factor is the wish of the (disabled) individual" (Snowdon 1976, p. 32). The wishes of the carer were seen as of equal importance in the Durham proposal for domiciliary respite care which would enable both disabled and carer to maintain or re-establish their community links and relieve their isolation.

### Proposed Organisation

The proposal considered the composition of the organising committee as the project sponsor with responsibility for the following areas:

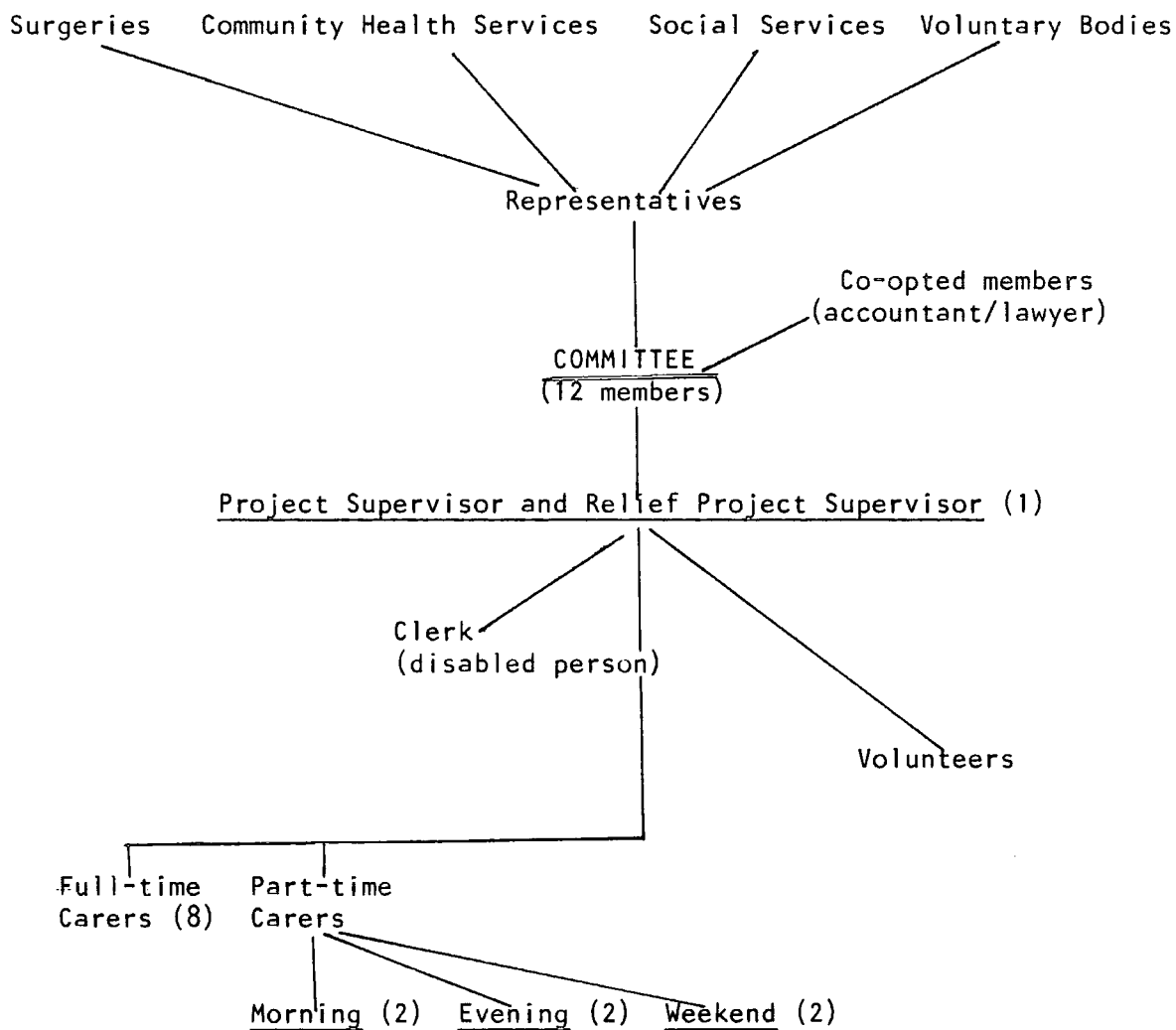
- a) appointing and training of supervisors and care staff;
- b) co-ordinating with caring agencies;
- c) fund raising;
- d) monitoring.

The Committee would include representatives from:

- a) social services departments;
- b) nursing and general practitioner services;
- c) voluntary bodies;
- d) co-opted members including carers, an accountant, a lawyer.

Figure 3.1 represents the envisaged organisation of the proposed scheme. The responsibilities of supervisory and care staff were based on the assumption that all caring tasks undertaken by the family should be carried out by the care staff as and when necessary. This meant some overlap of responsibilities with nursing personnel particularly

Figure 3.1

ORGANISATION OF PROPOSED CARE SCHEME

From Discussion Document, P. Brady, June 1983.

with bowel and stoma care. It was argued that these are daily care activities of family members looking after a severely disabled person at home and should come within the remit of a care attendant.

Funding was to be available from MSC government sources with privately raised funds to cover accommodation and travel costs. The proposal was distributed to health and social services departments, general practitioners, nursing and paramedical services, voluntary organisations and city and county councillors. The MSC was approached and consideration given to an appropriate agent.

#### Motivation for the proposal

It is pertinent to the subsequent description and analysis to identify the motives for the initiator's proposal as they gave weight to the arguments for support for the scheme during the initial debate. In her early 40's she had cared for her ailing husband for ten years. Over the previous two years his condition had deteriorated markedly and the needs she identified for herself were the outcome of experience. Service provision for the severely disabled at home did not extend in Durham to giving any domiciliary respite to the carer. Nursing services offered to the family were task oriented and available once a fortnight for bathing her husband and for a short period, while there was a need, a nurse attended daily to dress his bed sores. Through the social services department a number of pieces of 'hardware' such as grabrails for the bath, trays and wheelchairs were provided and the nursing services arranged the delivery of a bed and a hoist but no follow up instructions on use or assessment of their suitability was carried out.



The values underlying the proposal were:

- a) the rights of individuals to make choices about their place of abode and care;
- b) the rights of carers who have substantially restricted lives to have relief from their responsibilities;
- c) the rights of all people, regardless of disability or responsibilities, to lead as full a life as possible.

These values of 'normalisation' (Wolfensberger et al 1972, Durand and Neufeldt 1980, O'Brien 1981, Blunden 1985, Edwards 1985, Williams 1985) associated usually with the social integration of mentally handicapped people can be applied equally to any disadvantaged group. They influenced the job description of staff and the general enabling philosophy which encouraged taking people out of their homes if they so wished.

The emphasis on the trial nature of the proposed project and the suggestion that it should be adopted by the social services department was indicative of the initiator's political philosophy and belief in state support for the disadvantaged.

The values described were personally held beliefs and as Handy (1981) points out as such cannot be "contradicted, denied or regulated by others." As the essence of the emerging organisation the values held by the initiator were profoundly important. They influenced essentially like minded volunteers who became involved in the committee and affected the statutory body representatives' brief as co-opted

members. Most importantly they raised the aspirations of caring families.

### ORGANISATIONAL PLANNING

The 'program planning model' of Van de Ven (1980) implies consciousness and understanding of the stages of development up to 'Program Activation'. It is not suggested that such deliberateness was part of the early stage of Durham Community Care but the resultant pattern was similar. Figure 3.2 illustrates the six stages of the PPM. Van de Ven acknowledges that these stages are very broad and overlapping. However, they do provide a guide to planners when considering new initiatives and are used to show the stages in the creation and development of Durham Community Care.

The greatest overlap of phases occurred between phases 5 and 6. They shared a continuity of goal in the consolidation of a service to be taken over by a different funding agent, as the non-static nature of the organisation became more apparent.

Such fluidity, which increased during the third year of operation (after the end of the research programme), was characterised by uncertainty about the future care of families, staff shortages, and accommodation difficulties, personality conflicts and policy differences. Handy (1981) describes all these problems as first level problems. He argues that such presenting problems are particularly symptomatic of voluntary organisations reflecting underlying issues of goals, values, relationships, decisions and people.

Figure 3.2

THE SIX STAGES OF THE PPM APPLIED TO DURHAM COMMUNITY CAREPLANNING1. Prerequisite

Identity  
Complexity  
of problem or  
goals to be  
dealt with.

2. Problem  
Exploration

Involves uses  
to identify  
need prior-  
ities.

3. Knowledge  
Exploration

Involve experts  
to reconcept-  
ualize problems  
and identify  
alternative  
solutions.

4. Program  
Design

Involve  
affected  
parties in  
developing new  
program  
proposals &  
implementation  
of plans.

ACTIVATION5. Program  
Activation  
& Evaluation

Trial Implemen-  
tation and  
formative  
evaluation of  
new program.

6. Program  
Generation/

Institution-  
alize program  
as ongoing  
activity and/  
or transfer  
program to  
adopter.

12 months

Crossroads  
Steering Cttee2 year  
(research  
project)Working in  
tandem with  
Durham  
Community  
Care

Yr 3

Crossroads

To initiate a plan to meet  
local community needs.

- a) Innovator identifies goals of a scheme to satisfy personal needs.
- b) Canvas of opinion of carers in MS society, and interested friends and acquaintances.
- c) Canvas of opinion of Statutory & Voluntary Caring agencies via distribution of proposal.

- a) Study of comparative schemes.
- b) Involvement of experts from vol. agencies operating respite & funding agents and academic advisor.
- c) Newspaper survey of carers - trawl.
- d) Document-ation of meeting & dissemination.
- e) Research diary started.

- a) Continue dialogue with H/A & S/S at senior and local level. Gain co-operation for training programme.
- b) Establish credibility and clarify role of C/H vis-a-vis H/H & D/N.
- c) Dialogue with & clearance from TU.
- d) Submission of funding application to chosen CP agency.

- a) Pilot project commences. 12 mos renewable MSC funding. Researcher member of management committee.

- a) Institutionalization of programme. Review of resource and allocation variables. Consideration of transfer to Crossroads

From Van de Ven & Keenig (1976) Normative model of program planning & evaluation process.

The methods used to analyse these developmental problems are based on the three management areas identified by Tichy (1980). Technical, political and ideological they refer to Handy's 'second level issues' - the management of deeper problems arising from values, relationships, goals, decisions and people. The 'management' of such issues together with the recognition of external influences in an organisation's development and the way such influences are utilised reflects its approach to change.

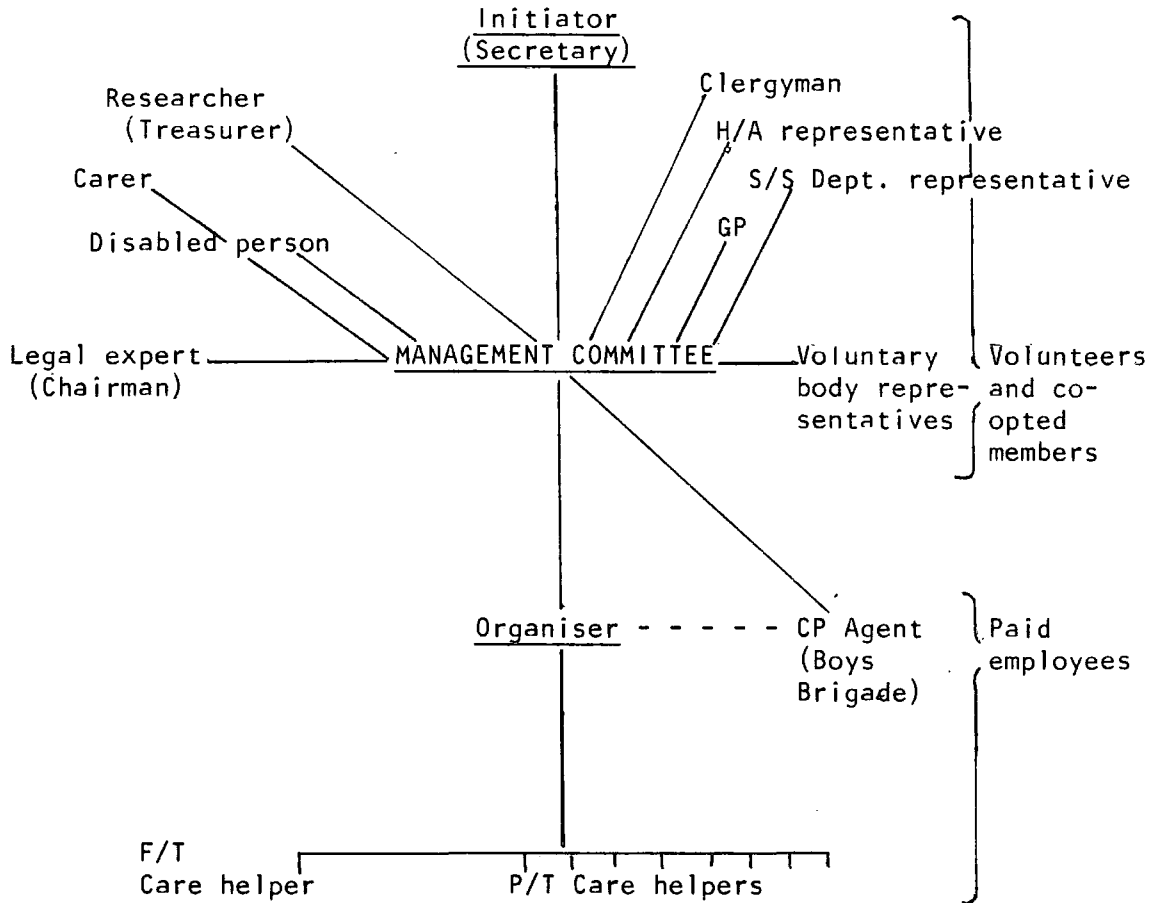
The differences between the proposed organisation (Fig 3.1) and the structure of the management tree at the start of the scheme's operation (Fig 3.3) reflect 'technical' influences:

- the funding restrictions affected the number of carers (and consequently) their working hours.

and political influences:

- The management committee enjoyed wider representation than the proposal envisaged with the inclusion of a disabled person and a research worker.
- The decision process, the holding and dissemination of information, and the relationship between management and employees, which were complicated by the necessity of using an MSC agent, were directly bound to the technical problem of funding. The use of an agent when applying for and receiving MSC funds was usual for small charitable organisations and pilot projects, as it

Figure 3.3

ORGANISATIONAL STRUCTURE AT 'ACTIVATION' (Phase 5)

relieved voluntary management committees of the need to negotiate directly with the MSC and handle wages. The Durham Community Care scheme used as its agent the Boys Brigade Community Programme Agency, which ran several local projects.

#### DEVELOPMENT OF SCHEME

Gerard (quoted by Handy 1981) lists a number of characteristics which are typical of voluntary organisations and were shared by Durham Community Care. For example:

- The essentially value based and intangible nature of much of the work and the lack of any suitable overall performance measure analogous to 'return on capital' in industry.
- The fact that in law the management functions are vested in Trustees and Board members who are typically part-time and often remote from day to day operations.
- The employment of a volunteer component in the work force with consequent problems of recruitment, selection and maintenance of commitment.
- The lack of client feedback - the cost and complexity of devising arrangements to assess client's reaction.

- The divorce between funding arrangements (convincing sponsors) and the quality and relevance of service provision (meeting clients needs)".

Gerard. The Voluntary Sector Profile  
quoted by Handy (1981, p. 3)

In an attempt to avoid some of those characteristics most likely to give rise to management problems the committee made the following decisions:

- a) not to use volunteer care staff because of the difficulties of recruitment, training and supervision;
- b) to canvas feedback from clients by involving carers as members of the committee;
- c) to instigate a research programme focusing on consumer response.

The research programme was carried out at no cost to the organisation. The remaining characteristics identified by Gerard (1981) and discussed by Handy (1981) correspond loosely to the three ongoing dilemmas or issues which Tichy (1980) considers confront all organisations. These are:

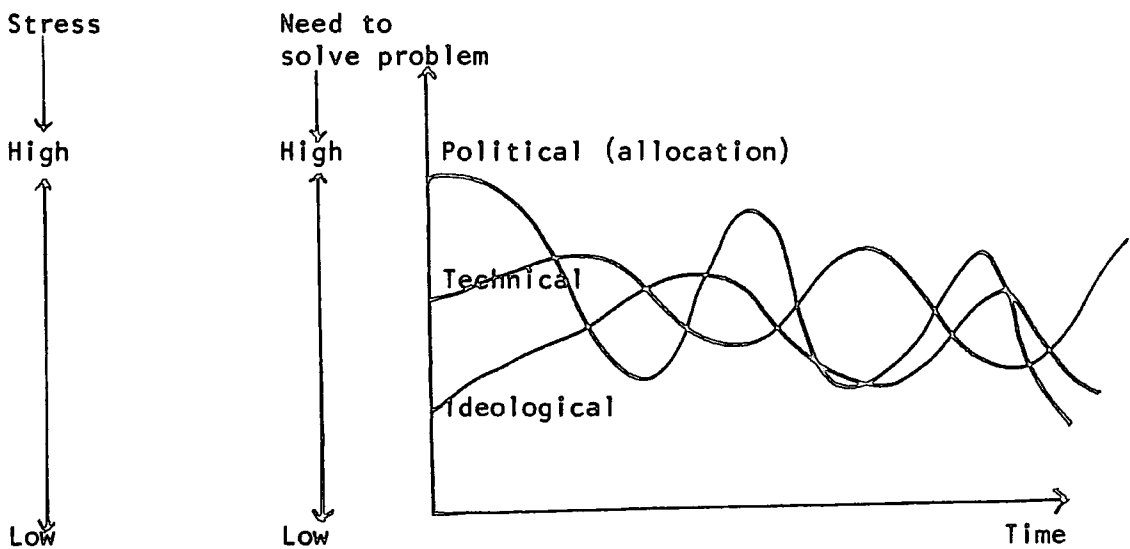
- the ideological and cultural mix problem, i.e. how ascendant values are determined. (the value base - Handy 1981).

- the political problem of distribution of power, (the management function distribution - Handy 1981)
- the technical design problem of how desired output is generated i.e. the generation of funds for the scheme and the continuity of funding. (the conflict between convincing sponsors and meeting client needs - Handy 1981).

In Tichy's (1980) view none of these problems is ever entirely resolved, and at different points in time any one area may need adjusting. Figure 3.4 illustrates the peaks and troughs in problem resolution over time.

Figure 3.4

PROBLEM RESOLUTION GRAPH



from Tichy (1980)



The model shows the wave like nature of crises and Tichy suggests that development of organisation is better likened to strands in a rope than a biological life cycle analogy. Separating the strands aids understanding and this exercise will be attempted in the following sections which examine the ideological, technical (financial) and political (allocation) elements in the development of Durham Community Care.

The starting point of the organisation has a crucial place in the analysis, in Tichy's view because, he argues, the dominant strand at the time of creation of the organisation has the greatest effect on its development. In the case of Durham Community Care the dominant strand was ideological. Resolution of ideological dilemmas at an early stage may have reduced later problems but only hindsight can furnish such knowledge and could not be obtained within the period of the research project.

### Ideological Issues

Gerard (1981) points out that voluntary organisations are involved in essentially 'value based' work. It is not surprising therefore that the dominant strand (Tichy 1980) at the start of Durham Community Care was the ideological strand. These values and beliefs were personally held convictions of the participants but, although not open to challenge, as Handy recognises, they could still be problematic if there was a difference of interpretation over:

"the ultimate purpose or worth of an activity (the 'why' value) and feelings about the way in which that work should be carried out (the 'how' values)"

(Handy 1981)

The practical nature of the scheme as a means of meeting needs influenced the initial committee membership. The initiator maintained considerable influence over the embryonic organisation. As a consequence, in the first year of operation the campaigning element in the proposal to ensure a long term improvement in the 'quality of life' of disabled people and their carers, came to the fore.

A conflict of ideological priorities between care givers and campaigners became evident within the committee and affected relationships between the initiator and the organisers (paid staff).

The conflict in the committee revolved around Gerard's question of 'whether (an organisation) is intended to work within the existing social framework or seek to change it' (Gerard 1981). Kimberley (1980) speaks of the need for 'good will' to accommodate experiment and change until roles are defined and consolidated through their institutionalisation. Good will was nurtured by the committee who supported the organiser and staff in regular informal meetings encouraging co-operation and staff commitment. However, conflicts arose between individual committee members, between committee members and the organiser and between the organiser and the senior care helper (full-time worker). The conflicts centred on management style, crystallising in the issue of who held ultimate managerial responsibility, the voluntary management committee, paid organiser or funding agent.

The short term responsibility of the researcher was that of an enabler. By providing the means of accounting and reporting information (the collection of data in the monthly statistical returns, design of referral and assessment tools) some of the organiser's practical tasks were structured. Guidance on criteria for accepting families could then be debated by the committee, with the participation of the organiser and based on knowledge of the demand for the service.

Knowledge of the size of the gap in statutory services to carers caused a dilemma over the direction of development and the role of the committee as a 'pressure group'. The questions posed revolved around whether the committee should use its increasing knowledge of the gap as the pilot project proceeded to concentrate on:

- a) campaigning for the maintenance of Durham Community Care;
- b) campaigning for an increase in statutory and existing voluntary provision;
- c) launching a public campaign for the rights of carers;
- d) consolidating the service and using its influence to increase the statutory services commitment to the scheme through joint funding or main health or social services funds.

The latter course (d) was followed. This incorporated the campaigning elements of (b) and (c) and led to a high public profile for the scheme.

The committee members who could not accept the dominance of the campaigning element resigned. Personal conflicts were reduced through the departure at the end of his MSC contract of the senior care helper,

the institutionalisation of office procedures and communication channels and an increasing awareness on the part of committee members of their functions.

### Technical Issues

MSC funding of Community Programme projects has one primary aim - to re-introduce the long-term unemployed to employment by providing financial backing for schemes which can benefit the wider community through the employment of such people. The CP backing has disadvantages and for this scheme the funding created problems which revolved around two issues:

- a) restrictions on the use of funds;
- b) uncertainty about the future of funds.

These technical (funding) issues (Tichy 1980) had an impact on the political (power) dilemmas faced by the scheme in its management and in the need to resolve ideological problems concerning the responsiveness of the scheme to the long term needs of the carers.

### Restrictions on the use of funds

The restrictions on the use of funds extended to three areas presenting problems for the voluntary management committee:

- A. restrictions on the committee as an employer,
- B. demands exerted over the commencement of the project,
- C. restrictions on budget allocation.

A. The restrictions placed on the management committee as an employer were:

- a) The employment of a certain ratio of part-time to full-time staff and supervisors.
- b) Part-time work defined as 24 hours a week to be worked on 3 days between 9 a.m. and 5 p.m.
- c) Maximum pay rates based on nationally agreed averages.
- d) Strictly enforced eligibility criteria for staff who had to be in receipt of certain state benefits prior to appointment.

Negotiations between the sponsor (the initiator) and the Community Programme agent (The Boys Brigade) resulted in some flexibility over working hours; five day a week working for each care helper at flexible times which enabled the scheme to offer 24 hour a day seven day, a week respite care. After ten months overnight cover was prohibited by the MSC and eventually further eligibility restrictions, i.e. the exclusion of married women who were not registered unemployed in their own right and whose husbands were working, made recruitment of suitable staff very difficult.

B. The demands made on the committee for the commencement of the scheme took the form of a time limit on the selection and appointment of staff. Funds were made available very quickly, within six weeks of a formal application, and the scheme had to be fully operational within four weeks which presented problems in filling 24 hours a week for each of nine staff when few families had been referred to the scheme.

C. Budgeting of resources followed a set CP format with insufficient allocation of funds for training or the travel expenses of care helpers.

### Funding uncertainty

The day to day problems of funding were overshadowed by uncertainty over long-term support. MSC funds are allocated on a 12 month basis, only the key post of organiser being renewable. The management committee evolved funding goals and means designed to reduce the uncertainty. These were:

A. To follow course (d) (p. 65). In an attempt to resolve the ideological dilemmas by consolidating the service and using its influence to increase the statutory service commitment to the scheme through joint or main funding, the committee decided to apply for secure funds from:

- joint funding (health and social services)
- main social services or health authority funds
- European Economic Community funds.

B. In the event of failure to re-apply for MSC funds

C. To fund raise to provide an independent income.

The decision to fund raise resolved some of the uncertainty about future resources. It overcame a cash flow problem imposed by budget restriction, creating money for training and established a reserve to pay care helpers between MSC years when the problem of lack of

continuity of staff was compounded by training needs of new staff. In the event the decision prevented the collapse of the service. Secure funding was rejected at the end of the first twelve months of operation and at that trough in the technical wave of development (Tichy 1980) morale of volunteer managers (committee members) and paid staff was very low. The security of the service was only possible through privately raised funds until a second group of MSC funded staff was appointed and trained.

### Political Issues

The political issues - the allocation of power - were at times the source of considerable problems to Durham Community Care.

The organiser, a paid employee, was service oriented, keen to establish a scheme with high care standards, a good rapport with families and staff and a satisfactory working relationship with referring agents. Strong directive office management was neither her style or, for her, a high priority. Her natural orientation created problems which were compounded by lack of clarity over her responsibilities and those of the committee. Personality differences between organiser and initiator exacerbated the problem over accountability to the management committee. The problems over areas of responsibility and ultimate authority were uneasily resolved by:

- a) insistence on a direct line of communication between the committee chairman (the sponsor) and the CP agent on policy matters such as appointment of staff, hours of employment and monitoring of the scheme by the MSC,

- b) support for the organiser with weekly informal meeting with the executive, to discuss day to day issues,
- c) the implementation of a record keeping system.

The consultative sharing type of organisation is described by Kimberley (1980). In such a type the initiator inspired goals are discussed and implemented with the co-operation and participation of all staff. This proved as elusive a goal for the Durham scheme as it did for the medical school described by Kimberley and a more directive form of management emerged which reflected the accountability of parties to the scheme. Figures 3.5 and 3.6 illustrate the realignment of the structure of Durham Community Care after 12 months of operation.

The issue of accountability, that is, who had ultimate responsibility for the service provided to carers, was a recurring problem for the emerging organisation and the importance of the committee's acceptance of responsibility for standards of care meant a need for information and clear channels of authority. The directive management tree in Figure 3.6 clarified the communication process.

Miles and Randolph (1980) discussing the learning styles of emerging organisations have a parallel in the development of the management structure of the scheme and its move towards a directive model. The open, consultative model of shared experiences (Fig. 3.5) is a re-active learning framework which the authors feel is most likely to occur in an innovative setting where outside constraints do not pressurise the learning and decision making process. The pro-active



CHANGES IN MANAGEMENT STRUCTURE OVER 12 MONTHS

Figure 3.5

CONSULTATIVE MANAGEMENT

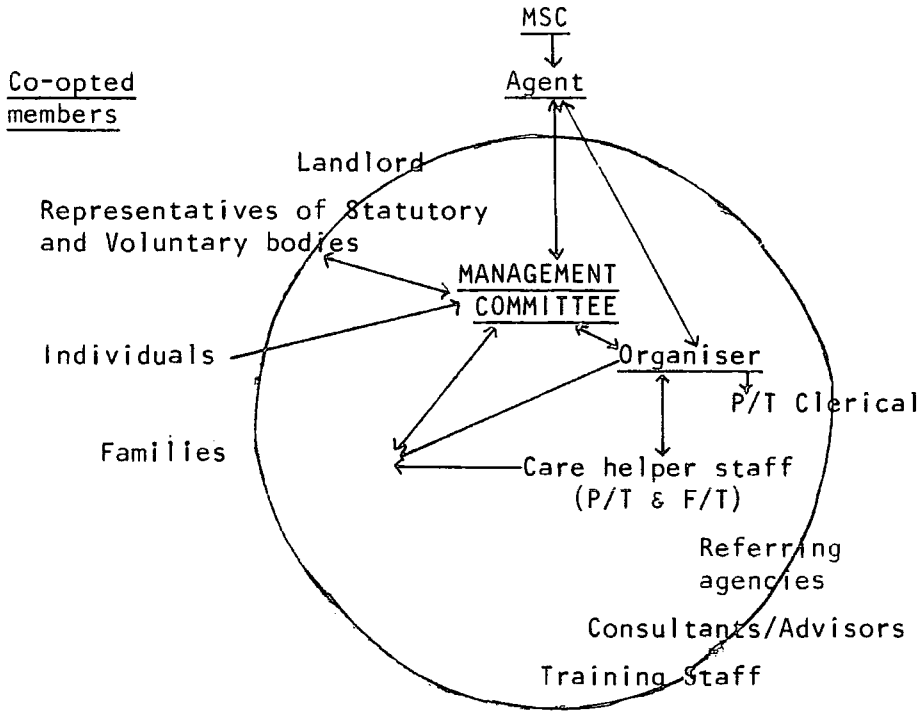
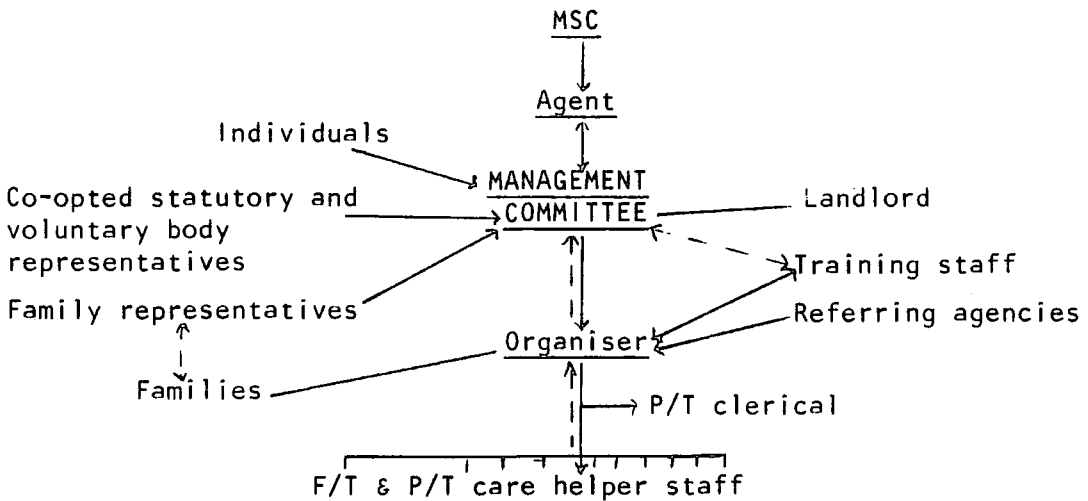


Figure 3.6

DIRECTIVE MANAGEMENT



model, which Miles and Randolph consider fits an organisation whose originator and collaborators possess a fund of knowledge, relating specifically to predicted problems, provides a positive initial management base, but a less flexible response to change. All organisations have a mix of learning styles and the predominance of any one at any time will effect the response in the organisation.

In the development of the present scheme a strong pro-active learning process had created a fund of knowledge which was self generating. The development threat to a pro-active style occurs when new situations arise to which the knowledge fund has no answers. The scheme managed this problem by calling in specialists to provide the committee with particular skills. The most influential specialist was the Crossroads Regional Development Officer whose involvement in guiding the development of the scheme resulted from the technical decision to work towards securing funding and the ideological decision to maintain the values of the organisation. These aims could, it was felt, be achieved only by changing the political structure of the committee and becoming a Crossroads Care Attendant Scheme Steering Committee.

#### THE INFLUENCE OF ENVIRONMENTAL ISSUES ON ORGANISATIONAL DEVELOPMENT

It is not possible for any organisation, to exist in isolation from the wider environment in which it operates. The ways in which management utilises the 'publics' with which it associates reflects and influences internal issues (see page 74). Kotler (1982) groups publics in the following way:

- a) 'input publics' - which supply resources to an organisation,
- b) 'internal publics' - which convert resources supplied into useful services,
- c) 'intermediary publics' - which maintain the quality of useful services and provide a link between the useful service and its consumers,
- d) 'consuming publics' - which consume the useful services.

Figure 3.7 applies the model to Durham Community Care. It has been noted (Penning, Van de Ven 1980) that the early stages of an organisation are closely related to external influences, that is the originator's susceptibility to particular 'publics'. The consumer orientation of Durham Community Care is a reflection of the originator's experience and particular susceptibility to 'consuming publics' of in particular, local carers and the Association of Carers. The development of the scheme was characterised by a shift in the response to and utilisation of its 'consuming publics' (families, statutory services, media) by the 'internal publics' (management committee and staff).

The client orientation was emphasised and exploited. It was used in dealings with all the 'publics' to achieve the desired standard of service and in pursuit of continuity of provision. The utilisation of 'publics' fall into four areas by activity:

- a) opportunistic use of other 'consumer publics' in order to maintain a high and positive profile achieved through use of the press and by lobbying city and county councillors,

Figure 3.7

APPLICATION OF 'PUBLICS' MODEL TO DURHAM COMMUNITY CAREThe Main 'Publics' of Durham Community Care

<u>'Input Publics'</u>	<u>'Internal Publics'</u>	<u>'Intermediary Publics'</u>	<u>'Consuming Publics'</u>
Donors Suppliers Regulatory Publics	Management Committee Staff	Facilitators	Clients General Publics Activist Publics Competitive Publics
- MSC funding agency	- responsibility for policy	- referring agencies	- carers and dependants
- public subscribers	- responsibility for day to day running	- training (statutory bodies)	- county council and city council
- social services dept. health authority	- care helping staff	- landlord	- press - radio
- stationary suppliers		- care helping staff	- social services department - nursing services
- reprographics			- voluntary organisations - Assoc. of Carers  - Crossroads

From Kotler (1982)

b) clarification of the services' role with other caring agencies who were:

- competitive 'consuming publics' (statutory agencies at field level - social workers and district nurses)
- facilitators or 'intermediary publics' (referring agencies)
- potential donors or 'input publics' (funders)

c) clarification of the goals to ensure maintenance of a respite service for carers, through collation and utilisation of research findings by 'internal publics' (committee and staff),

d) pursuit of these goals in relation to 'input publics' (funders).

The effectiveness of the scheme, the interdependence of the four 'publics' and their impact on ideological, political and technical development issues are explored in Chapter 9.

CHAPTER 4METHODINTRODUCTION

The researcher carrying out the evaluation of Durham Community Care Domiciliary Respite Scheme was a member of the planning group and subsequently served on the management committee as treasurer. This level of on going participation afforded ample opportunity for collection of data prior to the start of the scheme and for the feedback of information for the development and improvement of the scheme as the data from surveys became available.

Five surveys were carried out as the major element of the evaluation. All took place within a two year period, July 1 1984 - June 30 1986 and they will be described in chronological order. The pilot study for the main carers' survey was carried out between February and March 1984.

Additional data were obtained from:

1. A diary, kept between July 1983 and June 30 1985 which gave an account of all meetings, telephone calls and action taken by the planning group and by the executive.

2. Access to documented data held in the office accommodation which consisted of case files, correspondence and weekly diaries completed by each care helper.
3. Statistical returns on referrals and caseloads made available to all committee members at each monthly management committee meeting.
4. Audited annual accounts of the charity.
5. The written report of the organiser to each meeting.
6. Verbal reports from the Manpower Services Commission agent on MSC monitoring visits.

#### GEOGRAPHICAL AREA AND POPULATION

The geographical limits of the scheme were based on the Durham City administrative area (see map Appendix 1). This is roughly co-terminous with the local authority Social Services Department's Central area. The county council population estimates for 1985 based on 1981 census returns were 82,700 inhabitants in an area of 73.24 square miles (Durham County Council 1986). The city centre is prosperous and residents enjoy a relatively low level of unemployment (5.5%) compared with less affluent surrounding areas (up to 11.8% in Coxhoe and 23.4% in New Brancepeth for example) (OPCS 1981). The areas surrounding the city have suffered from a decline in standards of living since closure of collieries which had provided economic stability.

The national survey "The Handicapped and Impaired in Great Britain" (Harris 1971) allowed for regional and demographic variables and although somewhat dated, does give an indication of the potential numbers of handicapped people aged over 16 years in a given population. Based on the figures there could be at least 4,936 handicapped people living in the research area (7.75% of the population over 16 years). Harris (1971) categorises handicap according to levels of disability and within her categories 1-6, ('appreciably' to 'severely' handicapped) are an estimated 2,530 people over 16 years of age living within the area. The figure could be much higher, Taylor (1981), for example, suggests that Harris seriously underestimates numbers of physically handicapped people living in the community.

## THE SURVEYS

### Survey 1: Survey of Carers

#### Pilot study

A small pilot study was conducted to test a method of identifying carers and a proposed interview schedule. The survey was carried out between February and March 1984 prior to confirmation of funding of the respite care scheme.

An advertisement (Appendix 2) was placed in a local parish magazine inviting carers to contact the researcher if they were willing to discuss their situation. This produced one respondent who was interviewed using a schedule developed from exploratory discussions with two known carers. The interview was semi-structured with a number of open ended questions and lasted one and a half hours. Identical



advertisements were placed in two free papers delivered within the study area in two consecutive weeks in March 1984, these produced a response from four carers who agreed to be interviewed. On the basis of the five pilot interviews a modified interview schedule was developed for the main study. The method of identifying carers described above for the pilot survey was chosen for the following reasons:

1. Carers may be unknown to the health (nursing) or social services departments. Such agencies are orientated towards the disabled person but not all dependants require nursing services and social services departments may have incomplete registers of the physically handicapped. Using statutory agencies' case records may not therefore reveal the extent of caring in a particular area.
2. General practitioners (GPs) are likely to know which families are caring and under pressure, however the use of practice lists was discounted because:
  - a) there was insufficient time to negotiate access to records;
  - b) GP judgements, like those of all health care professionals focus primarily on the dependants. (It is the policy of the Association of Carers to advise carers and dependants to register with different general practitioners). Medical records may not, therefore, give a reliable record of carers' problems although prescription of tranquillisers or relief for back pain may indicate new or recurring care related health problems. Use of

intermittent care for the dependant could also be noted. Even if access to records had been given, scrutinising case files in such detail and discussions with GPs on the implications of the study would have required more time than was available to one researcher.

3. The consumer origins of the scheme rendered appropriate the use of public methods in seeking self selected carers to identify a population for the pilot survey which was unknown to likely referring agencies.

The disadvantages of the method used arise from three limiting factors:

1. The reliance on carers' self identification excluded, at the pilot stage, those who did not recognise or give much consequence to their caring responsibilities.
2. For reasons of cost and lack of time the weekly newspaper advertisement ran for only two weeks. Wider advertising might have resulted in a higher response.
3. The initiative to respond to the advertisement rested entirely with the carers who had to be highly motivated to make contact and/or have access to a telephone.

#### Main survey of carers

The population for the main survey of carers comprised the 153 carers (159 dependants) supported by the scheme between July 1 1984 and June

30 1986. An account of the process of assessment after referral appears in Chapter 5. The length of the research project gave an opportunity for a longitudinal study of carers. The method of sampling, therefore was chosen to allow for a study of the use of the service over time. Two surveys were carried out with an interval of twelve months, one in February-March 1985 and one in February - March 1986. The sampling frame of each survey comprised all the families visited during one seven day period. The 1985 (year 1) families numbered 43 and in 1986 (year 2) 37 families were visited. As the same sampling frame was used also for a study of the tasks performed by care helpers and the conditions within a family can change quickly, it was important to interview at an early date after the chosen seven-day period. Because of these considerations the number of families selected for interview had to be of a manageable size, while being as representative as possible.

The method of selection differed between years.

Year 1 A 30%\* sample was randomly selected from the 43 alphabetically listed families who had been visited. This produced 14 families. Two dependants died suddenly and it was decided for ethical reasons not to approach the bereaved carers. A third family was not approached for an administrative reason.\*\* All the available remaining families (11) agreed to be interviewed (100% response rate).

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\*All percentages are rounded to the nearest whole number.

\*\*Disciplinary measures were taken against one care helper immediately after the chosen seven day period. It was inappropriate to use any data which referred to families she had visited, or approach them.

Year 2 The sampling frame comprised 37 families, and 20 families (55%) were selected for interview. Nineteen agreed to be interviewed, a response rate of 95%. The sample was chosen by the following method:

1. All families were listed by date of referral and divided into two groups (A and B). No families had been referred in the four month period January 31 - May 31 1985).
2. Group A consisted of 19 families of whom 17 were referred in the first six months of the scheme, between July 1984 and the end of January 1985, and two who were self-referred at the pilot survey stage. This group included five families interviewed in year 1. They were re-interviewed, together with the two families from the pilot stage. Of the remaining 12 families nine were approached and all agreed to be interviewed. Three families were excluded because one dependant had recently died, one was in hospital and one carer was a Durham Community Care committee member. A total of 16 carers from the 16 available families in Group A were interviewed.
3. Group B consisted of 18 families referred in the six months between June 1985 and January 1986 inclusive. Two disabled people living alone with no immediate carer were excluded, together with one family where the situation was too difficult to permit intrusion.\* Four of the remaining 15 families were selected to

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\*A middle aged husband caring for his wife who was seriously ill with muscular dystrophy was under great strain. He was taking large doses of tranquillizers and could not be expected to cope with an interview.

represent families most recently accepted for domiciliary respite care. They were representative in terms of age and cause of dependency; the number was chosen to produce, when added to Group A, a manageable total of interviews to be conducted in a short period of time. One recently bereaved, very elderly, sibling carer declined to be interviewed. A total of three carers were interviewed from Group B.

The number of interviews conducted in Year 2 was 19.

A total of 30 interviews were carried out during Years 1 and 2.

Interviews were arranged within four weeks of the selection of families. Interviews were carried out in the families' homes, were semi-structured and lasted between one and a half and two and a half hours. They were tape recorded with the agreement of 21 families and a written record made of the interviews with those who declined to be recorded. Each family was given assurances that the interview would be treated confidentially and their anonymity assured.

The content of the interview included questions on the level of dependence of the disabled person and the effect on the carer of caring responsibilities. Questions on the level of dependence of disabled people covered mobility, self care activities on a scale of 1 to 3 according to ease of carrying out an activity: 1 - no difficulty, 2 - only with difficulty, 3 - cannot perform. Bladder and bowel control were similarly ranked in ascending order 1-3 on frequency of incontinence. Questions on cognition were coded 1-4 according to the degree of confusion: 1 - not at all, 2 - mildly, 3 - severely, 4 - very

severely. Questions on articulation, vision and hearing were coded 1-5 in ascending order of impairment and questions on the emotional state of the dependent person also on a scale of 1-5 in ascending degree of severity of affliction. The scores were based on observation in interview and comments of the carer and checked against information in the files. The score for the lowest level of dependency was a possible 27 and for greatest dependency a possible 88. The interview schedules appear in Appendices 3 and 4. The coding sheet is Appendix 5 and the interview manual Appendix 6. The questions relating to the carer and his/her capacity to care considered: health, age, additional responsibilities of children and work, the informal support available and the carer's relationship with the dependant. Coding was on a scale 1-5, for all but one question, reflecting capacity to care, giving a lowest possible score of 15 for carers least affected by their responsibilities and a maximum of 76 for the most affected carers (the question of employment, retirement and giving up work to care scored 1-6). An index was devised to give an overall score which reflected the dynamics of each caring situation. This was developed from Cantrell (1977 and 1985) and Lovelock (1979). A detailed account of the scoring appears in Chapter 7.

### Survey 2: Postal Survey of ex-Carers

A pre-piloted postal survey of ex-users of the scheme was carried out in April 1986, 21 months after the start of the scheme when 142 families had received or were currently receiving support. All 42\*

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\*26 families had a dependant who had died.

16 cases were inactive at the time of the survey.

ex-users were approached by letter and provided with a stamped addressed envelope for a reply. Twenty five replies were received, a response rate of 62%.

The purpose of the postal survey was to supplement the main survey by:

1. Including some people who may have received occasional relief and hence not been covered in the sampling frame.
2. Reaching families who had received care for a short time.

The introductory letter and questionnaire (Appendices 7 and 8) sought responses from ex-users on the nature of the dependant's disability, length of caring carried out, the support available to the family, the motives for caring and the effect of caring on the carer, and their opinion of the respite scheme.

### Survey 3: Door to Door Survey of Carers

In the second year of the operation it was decided to seek carers who were not known to the scheme and might be unknown to any welfare or referring agency. Throughout the first 18 months of the operation of the scheme there had been occasional local press coverage of the operation of Durham Community Care and the needs of carers. For this reason it was felt that the method of seeking self-identified carers through newspaper advertisements which was used for the pilot carer survey would probably yield a limited response if repeated, as some carers seeking support had been approaching the scheme themselves.

A door to door method was chosen because:

1. It was the most likely way of identifying carers receiving no statutory support.
2. It was the surest way of estimating the level of caring in the community.
3. It was a way of estimating the size of past caring activity.

Door to door surveys are extremely time consuming and for this reason it was decided to limit the size of the survey to two small areas within the city in the wards of Crossgate and Gilesgate Moor. The survey was carried out in May-June 1986. One hundred leaflets were delivered to households in an area of Victorian terraced housing and 149 leaflets on a 1960's private estate. Almost all houses were in owner occupation. The leaflet (Appendix 9) invited carers to make contact with the researcher and two carers did so, one in each area, both were interviewed using the main interview schedule.

A visit was made to each of the remaining leafletted households and two follow-up visits made resulting in an overall contact rate of 75%. The first three questions of a short questionnaire (see Appendix 10) were used to elicit the household composition. When a caring relationship existed or had existed within the past five years a brief interview was requested and carried out using the remainder of the questionnaire.

#### Survey 4: Task Survey

Two surveys were made of the tasks carried out by care helpers when supporting families. There was an interval of exactly one year



between the surveys which covered a seven day period in February 1985 and 1986. The survey data were collected in two parts and by two methods and were completed within 10 days of the end of the survey period. The weeks chosen for the main surveys of families provided the sample for the task survey. The data, therefore, refer to 38 families in year 1 (43 less the five families visited by the dismissed care helper which have been excluded from all task data) and 37 families in year 2. Details of findings appear in Chapter 5 and the task lists in the Appendix (11).

The method employed was as follows:

1. The organiser completed an information sheet on each dependant to be visited in the survey period (Appendix 12). This detailed the days and times of expected visits, their duration and purpose and indicated the nature of the tasks the organiser expected the care helper to perform while in the home. Additional information was sought on the likelihood of institutional residential care, intermittent or permanent, being sought, the organiser's assessment of the families' need for additional support if available from the scheme and the likelihood of each family accepting such an offer. The organiser thus provided:
  - a) a priority ranking of families;
  - b) a care plan for the week.
2. A task list was made available to each care helper prior to the start of the seven day period. Each was made aware of the purpose of the survey and encouraged to make notes on every visit made

during the week.

3. At the end of the week each care helper was interviewed and a task list completed for every family visited.

The task list covered the dependant's capacity for self care, the task carried out by the care helper, the whereabouts of the carer during the care helper's visit and the care helper's knowledge of other support services available to and used by the family. Care helpers were also asked about the length of their visits and their preparedness to use their own time to help families. The task lists were checked against the organiser's information sheets and the weekly diary completed by each care helper.

#### Survey 5: Staff Survey

Three methods were used to survey the care staff employed by the scheme:

1. The researcher participated in the selection interview of each care helper and semi-structured interviews were held with each person within six weeks of appointment. The post-appointment interview covered the care helpers' views of the training programme and their personal development needs. They were also questioned on their job expectations and their attitudes to their work including what they liked least and most about being a care helper.

2. Throughout the two year project the weekly allocation meetings were regularly attended. This gave an opportunity to observe and monitor the development of staff.
3. A postal survey of ex-care helpers was made in August 1986 to follow up their employment situation and ascertain the value of their care helper experience and training in their search for permanent employment. There was a 76% response rate to this enquiry (Appendices 13 and 14).

Semi-structured interviews were carried out with the organiser on three occasions. The frequency of contact with the organiser, both at weekly pre-arranged but fairly informal meetings of the executive, organiser and full-time care helper and on an individual informal basis made it possible to keep up to date with day to day affairs of the scheme.

The feedback of information was part of the role of the researcher. For this reason it was important to establish personal trust in the researcher and an understanding, on the part of all the staff, of the purpose of the research project.

## CHAPTER 5

### FINDINGS: DURHAM COMMUNITY CARE IN OPERATION

#### INTRODUCTION

This chapter describes the route by which families became known to and were supported by the scheme, the source of referrals and the assessment procedure used by the organiser. This is followed by an account of care needs of the disabled people and the tasks undertaken by care helpers. The chapter ends with a description of the care helpers, their background, recruitment and training.

The figures have been collated from the 28 day returns prepared by the organiser for the management committee and checked against the files. The data sheets were developed over the first six months of the scheme and detailed information was available from the 15th January 1985. Prior to that date the information on referrals was less comprehensive. The tables show the period divided into quartiles for easier presentation.

#### REFERRALS

##### Source of Referrals

The sources of referral are shown in Table 5.1. The figures in quartiles 1 and 2 show families referred and accepted for care.

TABLE 5.1

SOURCES OF REFERRALS THROUGHOUT THE STUDY

<u>Year 1</u>					<u>Year 2</u>					
SOURCE	1.7.84		15.1.85		SOURCE	QUARTILE 5	QUARTILE 6	QUARTILE 7	QUARTILE 8	30.6.86 TOTAL Yr 1 & Yr 2
	QUARTILE 1	QUARTILE 2	QUARTILE 3	QUARTILE 4						
Self	12	5	1	3	Self	1	6	3	3	34
Social Services	4	1	8	6	Social Services	1	11	6	7	44
District Nurse	18	7	7	4	District Nurse	5	16	6	3	66
Community Psych- iatric Nurse	7	2	1	1	CPN	-	1	3	4	19
Health Visitor	4	1	3	-	H/V	1	1	-	-	10
General Practitioner	-	-	-	-	GP	-	-	-	-	-
Occupational Therapist	-	-	-	1	OT	-	-	-	-	1
Warden	3	4	-	-	Warden	-	-	-	-	7
Voluntary Organisation	3	-	5	-	Vol. Org.	2	-	-	-	10
Family/ Friends	1	1	1	-	Fam/Friends	1	1	2	2	9
Others	-	-	2	2	Others	2	-	1	1	8
<b>TOTALS</b>	<b>52</b>	<b>21</b>	<b>26</b>	<b>17</b>	<b>TOTALS</b>	<b>13</b>	<b>36</b>	<b>21</b>	<b>20</b>	<b>208</b>

Quartiles 3-8 inclusive refer to all referrals made to the scheme and recorded. The 'other' category consists of four referrals from Chester-le-Street Psycho-geriatric Assessment Unit, one referral from a vicar, two from Crossroads Care Attendant Schemes (Northern Region) and one from the Association of Carers.

The high number (12) of self referrals in the first quartile reflects the origins of the scheme in a group of people with personal contact with carers. It was anticipated that the proportion of self-referrals would decrease until the scheme was sufficiently well known to generate a response from the general public.

The referral rate from the social services department and community nursing service remained fairly constant throughout the two year project. The large number (18:52) of referrals from community nurses in the first quartile possibly reflected the personal contacts made during the training of care helpers\*. It is also probable that the nursing service initially directed to the scheme families who had been known to them for some time, but subsequently referred new cases when the backlog had been dealt with.

The lack of referrals from general practitioners is in marked contrast with some Crossroads Schemes (Bristow 1981) and presumably

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\*The training programme for care helpers included a placement of 5 half days with community nurses in the first two weeks of their employment.

reflected the role of attached community nurses in those practices in Durham in which a GP's 'referring' responsibilities can be shared.

The voluntary organisations referred to are locally based groups such as Age Concern, the British Red Cross Society and a number of luncheon and day clubs. As with self help groups the personal contacts, visits and talks given by the organiser were a stimulus for such referrals.

Table 5.2 shows the source of referrals during the pilot project in numerical and percentage terms. The families referred by health visitors and occupational therapists appear with the nursing service referrals. The sheltered housing warden referrals are in the miscellaneous category 'others'. Including the four families referred from Chester-le-Street Assessment Unit, 46 per cent of all referrals originated from medical, para-medical and nursing services indicating, primarily, that the physical and mental capacity of the dependant was low and that some level of nursing care was required to maintain that person in the community.

TABLE 5.2

SOURCE OF REFERRALS AS PERCENTAGES OF THE TOTAL

SOURCE	SELF	D/N	CPN	HV/OT	S/S	VOL.ORG.	FAM/FRIENDS	OTHER	TOTAL
NO.	34	66	19	11	44	10	9	15	208
%*	16	32	9	5	21	5	4	7	100
		96 = 46%				34 = 16%			

\*All percentages rounded to the nearest whole number.

Referring agencies, most particularly district nurses and social services departments, are acutely aware of the size of the problem relating to the elderly. Sixty seven per cent of all referrals concerned dependent people over the age of seventy years.

Table 5.3 shows the ages of dependent people and period of the families' referral to the scheme. At the referral stage the level of dependency of each person cared for at home had been evaluated by the referee. The appropriateness of Durham Community Care support was determined by the organiser.

#### Assessment Process

The 208 initial referrals led to 202 visits to families by the organiser as shown in Table 5.4. No breakdown is available for the first six months and it is assumed all families were visited. The lower number of visits figure is accounted for by enquiries where the referral was withdrawn or the dependant died suddenly. There were also two referrals for people outside the catchment area which were dealt with by telephone call only.

Throughout the period eight families were re-referred. Three were referrals made by the district nurse, two patients had been in hospital and returned home and one had been referred initially by a voluntary agency and at the time the carer did not wish to pursue respite. Of the remaining families two were re-referred by the community psychiatric nurse and one was accepted, and three self-referrals resulted in families being cared for. A further eight families were re-visited by the organiser to see if they were interested in



TABLE 5.3

FAMILIES REFERRED BY AGE OF DEPENDENT PERSON AND PERIOD OF REFERRAL

Age in years	Number of referrals per age group in each quartile								TOTALS
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	
0-9	5		2	-	-	-	1	-	8
10-19	5		-	-	1	1	-	1	8
20-29	2		-	-	-	1	-	1	4
30-39	6		2	1	-	-	-	-	9
40-49	6		1	1	-	2	1	-	11
50-59	1		1	1	1	4	-	-	8
60-69	7		1	2	3	5	1	1	20
70-79	29		11	8	5	11	9	10	83
80-89	8		6	4	2	8	6	3	37
90+	4		4	-	1	4	3	4	20
<b>TOTALS</b>	<b>73</b>		<b>28</b>	<b>17</b>	<b>13</b>	<b>36</b>	<b>21</b>	<b>20</b>	<b>208</b>

TABLE 5.4

NUMBER OF FAMILIES REFERRED TO THE PROJECT AND OUTCOME OF ASSESSMENT VISITS BY QUARTILE

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	TOTALS
Referrals	52	21	28	17	13	36	21	20	208 (135)
Visits on first referral	NK	NK	29	17	11	31	21	20	202 (129)
Re-referral	NK	NK	1	1	2	-	3	1	(8)
Re-visits	NK	NK	3	3	-	2	-	-	(8)
Total assessment visits made	52	21	33	23	13	33	22	21	218 (145)
Total eligible	NK	NK	20	18	11	29	22	17	190 (117)
Total families receiving respite care for first time	52	21	16	11	5	20	17	17	159 (86)

\*Total figures in brackets refer to Quartiles 3-8.

domiciliary respite. These visits resulted in one new family. Two patients had been re-hospitalized, three had made their own arrangements for care and the remaining three refused the offers of help.

Including re-referrals and re-visits a total of 218 assessment visits were made in the two years of the pilot programme (145 assessment visits were made in quartiles 3-8). The 218 assessment visits resulted in 190 families being considered eligible for support.

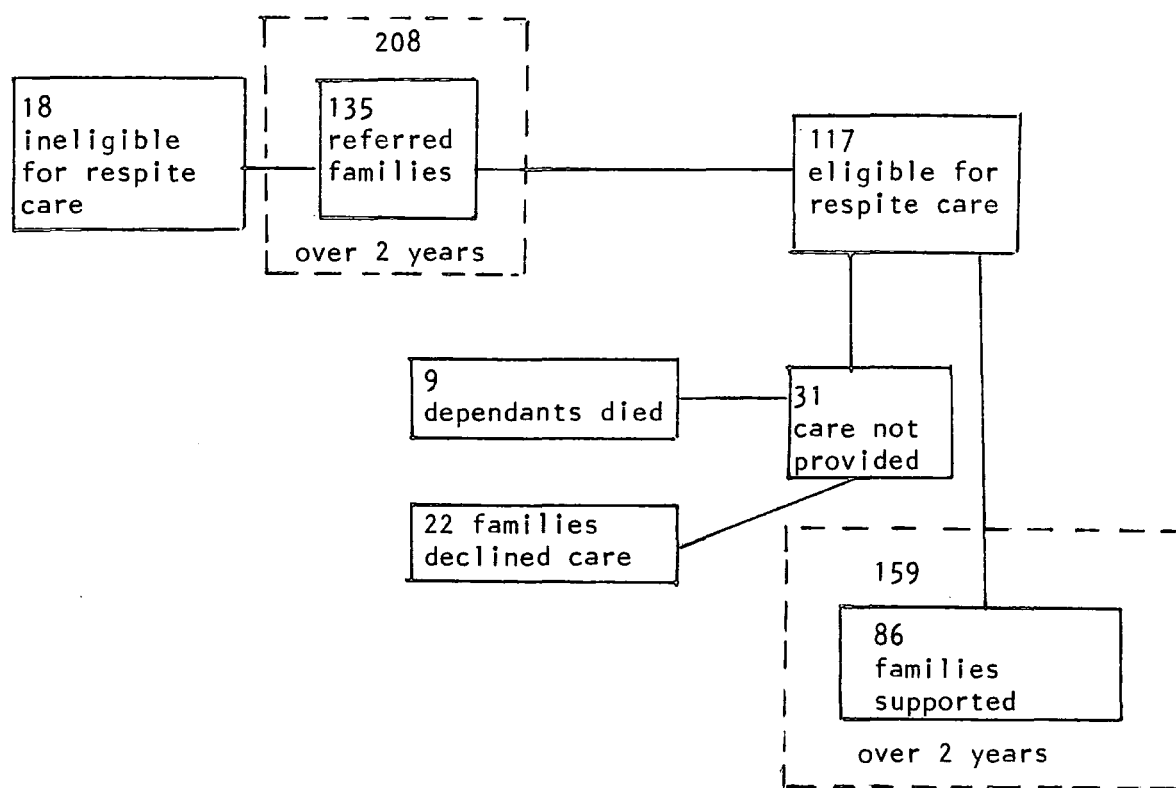
Figure 5.1 shows the outcome of referrals to the scheme taking account of the modification of recording and the greater detail in figures available after January 15th 1985.

From the 117 dependants whose families were considered eligible for support after 15th January 1985, 86 (73.5%) subsequently received domiciliary care. Over the total period of two years that number was 159, 73 dependants having been accepted up to January 14th 1985.

The discrepancy of 31 dependants arises from two factors. Firstly nine people had died between the assessment visit and the agreed start of the service. Services were arranged as quickly as possible, the next day or within three to four days, unless the family requested a delay. Secondly, 22 dependants and their families were considered eligible but declined the service. Table 5.5 gives a breakdown of the reasons the families gave for declining the service.

The percentage of referrals from the social services department where

Figure 5.1

OUTCOME OF REFERRALS TO DURHAM COMMUNITY CARE BETWEEN 15.1.85 - 30.6.86

N.B. Two year totals of referred and supported families appear within broken lines.

TABLE 5.5

FAMILIES DECLINING DOMICILIARY RESPITE CARE BETWEEN 15.1.85 AND 30.6.85

Reasons given by families	No.	Source of referral
Making own arrangement for support either more family input or private help.	9	4 self 5 social services
Do not feel in need of respite	4	1 DN. 1 HV. 2 social services
Too embarrassed	1	1 DN
Family think hospital is better solution	1	1 CPN
Think Part III accommodation is better solution	2	1 family. 1 CPN
Moving away	1	1 social services
Putting holiday arrangements first	1	1 CPN
Temporary problem solved	1	1 self
Changed mind	2	2 self
<b>TOTAL</b>	<b>22</b>	

families declined to accept help, is relatively high. The reasons for declining suggest that the social work referral and organisers' visits may have been catalysts for the families to re-appraise their respite arrangements. Another possibility is that the scheme was not clearly understood by social services department personnel or the family.

The high number of withdrawals from self-referred families indicated the need some families have for reassurance, perhaps over several months. Insufficient information is available on the families who declined help to do more than speculate on the reasons for their decisions.

### Eligibility Criteria

The organiser looked at the total family situation and applied broad guidelines when deciding who should be offered respite care. The guidelines used were those key factors identified by Bristow in her study of Crossroads Care Attendant Schemes:

- The health of the carer.
- The other commitments of the carer.
- The extent to which the disabled person can be left alone.
- The lack of anyone who can relieve the main carer.
- The need for help at times outside the remit of statutory services.
- Factors precipitating breakdown.

(Bristow 1981)

These factors are considered in detail in Chapters 6, 7 and 8. The objectives of the respite care offered reflected the cause of problems which the carer and organiser together identified and Table 5.6 shows the main reasons for accepting families compared with the Crossroads study. In five situations the relief of physical strain was the primary reason for accepting the family. There were additional benefits to them through the emotional support gained from sharing a task but the tasks were usually carried out in a short visit with the carer in attendance; help getting up in four instances and carrying downstairs in the fifth. The other reasons are not mutually exclusive and all relieve, to some extent, the general strain on a carer.

By far the greatest need has been for carers to have a break. The much higher percentage of daytime demand in Durham compared with the Crossroads sample perhaps reflected the number of older carers and dependants. The figures, however, represent the situation at assessment and care patterns developed in different directions.

The organiser considered 18 families to be ineligible for support (Tables 5.7 and 5.8). The role of the respite care scheme is primarily to relieve the pressure on carers and supplement not substitute for other services and it was the responsibility of the organiser to inform voluntary and statutory agencies and families of that role. The few requests from families outside the catchment area were particularly difficult to handle as the self-identified need of a family could not be met.



TABLE 5.6

MAIN REASON FOR ACCEPTANCE FOR CARE

Care provided to:	<u>Durham Community Care*</u>		<u>Crossroads**</u>
	no.	%	%
Aid the relief of physical strain alone	5	3	19
Aid the relief of general strain (following are not mutually exclusive)			
- Time to go out in evening on regular basis.	19	12	21
- Time to go out in evening on occasional basis (and)	9	5	
- have person put to bed by care helper.	21	13	-
- Time to go out in day on a regular basis.	80	50	16
- Time to go out in day on an irregular basis.	8	5	
- Prevent imminent breakdown.	7	4	9
- Enable carer to give time to other family members.	11	7	8
- Relieve marital stress.	4	2	4
Allow carer to go to work.	4	2	14
Allow carer to stay at work with peace of mind (popping in and out/preparing meals).	15	9	
Escort disabled person.	9	5	-
Enable carer to have weekend away.	1	5	6
Facilitate discharge from hospital.	2	1	2
Prevent immediate admission to hospital.	7	4	5
Help to get ready for day centre.	2	1	1
Help early morning before statutory services operate or at convenience of family to get disabled person up.	8	5	8
Put back to bed after statutory service hours.	16	10	5

\*Numbers refer to the incidence of a particular factor being considered to be a reason for care. Each family may be represented under more than one reason for care provision.

\*\*Crossroad Care Attendants' Scheme (Bristow 1981).



TABLE 5.7FAMILIES REFERRED AND INELIGIBLE BY SOURCE OF REFERRAL

SOURCE	YEAR 1	YEAR 2	TOTAL
	No.	No.	No.
Self	1	2	3
Social Services Dept.	-	3	3
District Nursing Services	-	4	4
Community Psychiatric Nurse	-	1	1
Health Visitor	-	1	1
Voluntary body	3	-	3
Family/Friends	1	1	2
Others	1	-	1
<b>TOTAL</b>	<b>6</b>	<b>12</b>	<b>18</b>

TABLE 5.8ORGANISER'S REASONS FOR INELIGIBILITY

Reasons	No	Source of Referrals
Sufficient care was being provided	7	1 vicar, 1 social services 1 family, 1 health visitor, 3 voluntary body
Other care considered more appropriate	5	1 CPN, 1 family, 2 DN.
Admitted into hospital	1	1 DN
Admitted into part III or private home	1	1 social services.
Different service more appropriate	2	1 self, 1 social services.
Other - e.g. Outside catchment area	2	2 self
<b>TOTAL</b>	<b>18</b>	

## CARE PROVISION

### Care Needs

The care provided to families was worked out with the organiser on the basis of the care needs of the disabled person and the respite needs of the carer. The timing and nature of that relief was arranged to suit the carer and was designed to give maximum benefit to carer and dependant.

Grouping the disabled people according to their self care abilities gives a picture of the help they required to be maintained in the community. Using the broad self care categories described also in Chapter 6 (p. 156) the dependants are shown to require a high level of support. They are grouped according to their capacity to carry out self care tasks in three areas of activity, toileting, feeding and mobility. Of the 159 dependants 43 disabled people (Category 1) were capable of no self care, 73 people (Category 2) were capable of one aspect of self care and 37 people could manage two aspects of self care (Category 3). The remaining 6 disabled people (Category 4) were able to perform each of the self care activities if supervised.

Table 5.9 gives a breakdown of the self care categories in terms of the age of the disabled person. It shows almost half of those people unable to manage any self care are over 70 years of age (28:43) and the small group of six people who require supervision only are under 50 years of age. The latter group were those with a mental handicap or in the case of one child, severe deafness.

TABLE 5.9

LEVEL OF DEPENDENCY OF DISABLED PEOPLE BY AGE GROUP AND CAPACITY TO PERFORM SELF CARE ACTIVITIES

Age	Unable to manage any self care without assistance	Capable of one aspect of self care	Capable of two aspects of self care	Capable of self care if supervised
	Category 1	Category 2	Category 3	Category 4
0-9	4	1	1	2
10-19	4	2	-	2
20-29	1	-	2	1
30-39	3	4	2	-
40-49	5	1	1	1
50-59	-	4	3	-
60-69	3	7	4	-
70-79	10	35	15	-
80-89	9	13	9	-
90+	4	6	-	-
<b>TOTALS</b>	<b>43</b>	<b>73</b>	<b>37</b>	<b>6</b>

Self care activity - toileting, including washing but excluding bathing  
 - feeding, after food had been prepared  
 - walking about a room.

### Nature of Support

The tasks carried out by the care helpers are discussed in terms of direct personal care and indirect care and divided into four broad areas of care activities; personal care, social activity within the home, domestic activity and social activity outside the home including escort duties.

Direct Care - Personal Care covers help with toileting and washing, including wiping hands and face after feeding, bathing, dressing, lifting and guiding.

Indirect Care - Social Care covers entertainment, conversation, watching T.V., making tea and coffee etc.

- Domestic Care covers preparing meals, or serving pre-prepared meals, cleaning, laundry and washing up.

- Escort Duties covers taking the dependant shopping, to visit relatives, hospital clubs or centres.

No category is mutually exclusive and usually more than one type of activity occurs within a respite session. Nearly half the families (71:155) had respite care more than once a week and in many of these the care patterns differed between visits. Table 5.10 shows the primary activity of the care helpers during their visits.

TABLE 5.10

#### PRIMARY ACTIVITY OF CARE HELPERS AT EACH VISIT

<u>Primary Activity</u>	<u>No. of disabled people affected</u>
Personal care	108
Social care	131
Domestic tasks	33
Escort	20

The self care capacity of the dependants and the care activities carried out by the care helper are examined below using the four categories outlined on p. 105 and Table 5.9.

#### Category 1 (n = 43)

Those people unable to perform any self care functions and their carers were supported by care helpers providing direct and indirect care.

Indirect social care of the disabled person was invariably associated with some other activity. In more than 50 per cent (23) of households with a totally dependent disabled person it was combined with personal care and in a further twelve cases with domestic activities.

Domestic activities carried out in families whose disabled member required total care (12) comprised preparation of a light meal at lunch time or, in three cases, preparing meals where the carer was elderly and frail and found difficulty managing to cook. This arrangement occurred on days when meals on wheels were not delivered.

One young wheelchair bound person was escorted by care helpers.

#### Category 2 (n = 73)

Nearly half of the disabled people were capable of one aspect of self care, usually feeding.

Ten disabled people capable of only one aspect of self care received three different types of support. They had an elderly or sick carer

and the combination of support, personal, social and domestic (in two cases escort) aimed to relieve some of the pressure on the carer.

Thirty seven disabled people capable of one aspect of self care were helped in two different ways and 29 required personal care in the absence of the carer.

In the remaining cases the care helper combined checking a disabled person left alone during the day with preparing or serving a meal, or escorting.

Of those requiring one type of support (26) nine were put to bed at night. The other people required social care during the day time when the normal carer was out, usually for a maximum of two hours to do shopping.

### Category 3 (n = 37)

Disabled people capable of two aspects of self care were helped primarily through one or two broad types of care.

Of the fourteen receiving one sort of support, ten received social support, two escort and two received personal care, one was put to bed and one had her surgical stockings removed three nights a week before going to bed.

The sixteen receiving two types of care were like those slightly less able people having a combination of personal and social care with three people being escorted shopping.

#### Category 4 (n = 37)

The least dependent disabled people were children and young mentally handicapped people who needed supervision at bedtime or were escorted to the Gateway Club.

#### Care Needs and Cause of Disability

Table 5.11 shows a breakdown of type of care by cause of disability.

Sixty nine per cent of disabled people received more than one form of support. People suffering from arthritis were rather more likely to require more than one type of care than the senile dementia sufferers. Those with a neurological disorder required personal and social care equally, whereas those with cardio-vascular problems or who were suffering the frailty of old age had a slightly greater need for social care than for personal care. This highlights a worry for carers whose dependants do not need constant attention but who risk falling or are in other ways 'at risk' if left alone.

Those with a disability present at birth required the broadest spread of support. They were the younger severely physically and mentally handicapped people who required intensive personal care, supervision, or were escorted to clubs. The domestic support comprised meal preparation as part of evening sitting care.



TABLE 5.11

TYPE OF SUPPORT BY CAUSE OF DISABILITY

Cause of disability	No. of disabled people	Types of care required*				Total of combined support
		Personal	Social	Domestic	Escort	
Arthritis	6	5	5	3	-	13
Neurological disorder	24	18	18	4	4	44
Cardio-vascular problems	33	23	27	6	2	58
Accident/disease	17	12	13	3	3	31
Paraplegia	1	1	1	1	-	3
General frailty	19	11	17	5	1	34
Mental illness	1	-	-	-	1	1
Senile dementia	39	25	35	6	4	70
Present at birth	19	13	15	5	5	38
<b>TOTALS</b>	<b>159</b>	<b>108</b>	<b>131</b>	<b>33</b>	<b>20</b>	<b>292</b>

\*individual dependants appear in more than one category

## CARE TASKS SURVEY

A detailed picture of the care tasks carried out by care helpers was obtained during two surveys of their activities over seven day periods in February 1985 and exactly 12 months later in 1986. The schedule (see Appendix 11) was completed by the interviewer, Figure 5.2 shows the number of tasks carried out by care helpers in each of the two survey weeks and Table 5.12 the accumulated incidence in each of the task areas.

In the 1985 survey week 43 families received support and in 1986 the number was 37. In each week nine care helpers including the senior care helper were involved in helping families. The support provided ranged from general supervision, entertainment by reading, taking a person out for a walk or to a club for handicapped people, to intimate care of pressure sores, changing incontinence equipment and dressing and undressing a person in the morning and evening.

In addition to support for the dependent person the care helpers carried out general household tasks in a third of the homes in both years. These tasks were mainly washing up and personal laundry, although beds were also made or changed in 1986. In 1985, 50 per cent of dependants had a drink or light meal prepared for them. A year later the proportion had risen slightly to 64 per cent. Personal care was still provided in two thirds of respite care situations but with more people being helped to get up or go back to bed in 1986. There was however a marked reduction in the number of households where the care helper administered medication (a drop from 30% to 10%). There is no suggestion of a change in management policy on the administering of

Figure 5.2

NUMBER OF CARING TASKS PERFORMED BY CARE HELPERS  
(Survey Weeks 1985 and 1986)

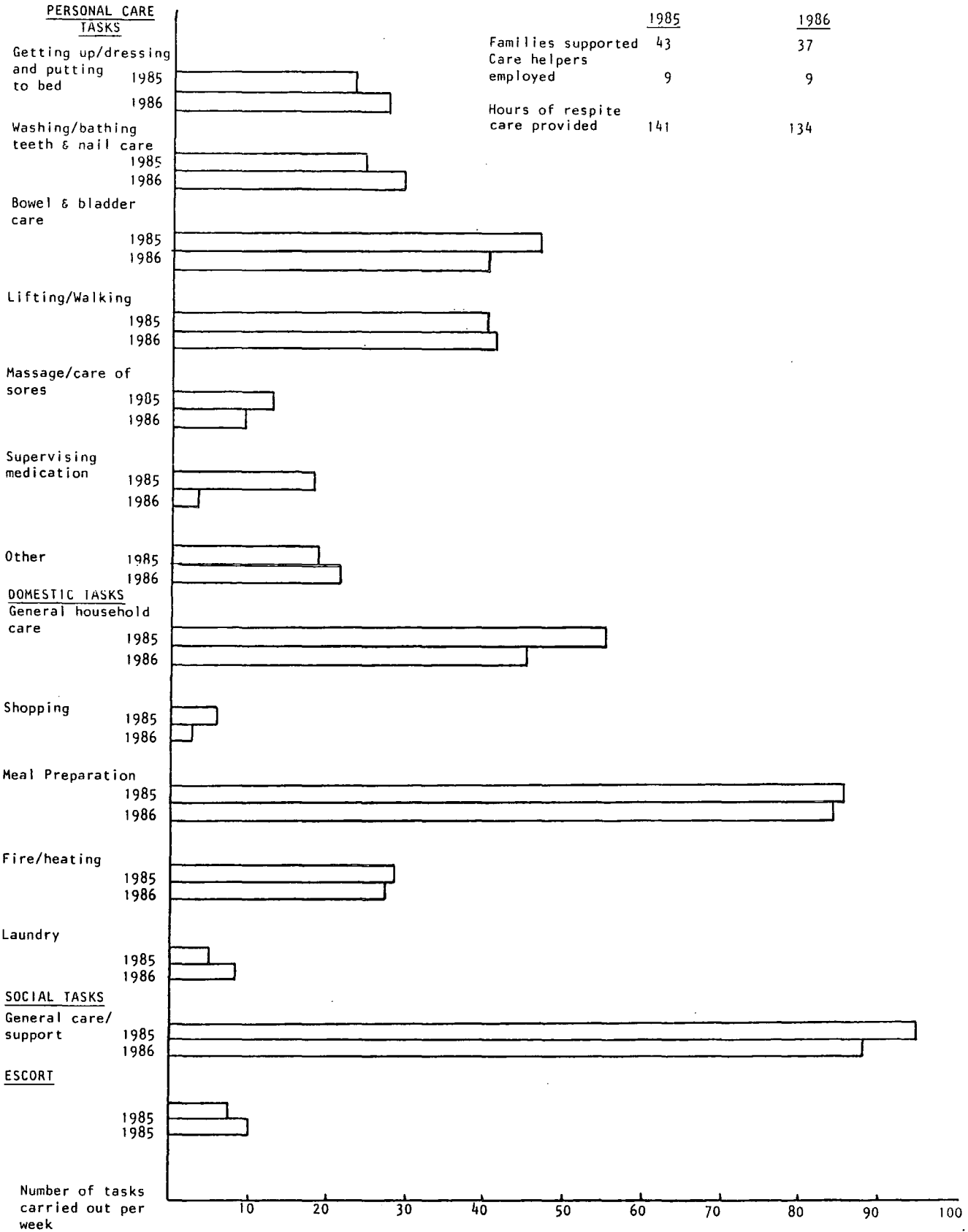


TABLE 5.12INCIDENCE OF TASKS PERFORMED BY CARE HELPERS IN SURVEY WEEKS

Nature of tasks	1985	1986
Personal	163	150
Domestic	172	156
Social	95	88
Escort	8	13
Support outside remit	14	19
Care helper extending visit beyond allocated time	20	17
<b>TOTALS</b>	<b>472</b>	<b>443</b>

drugs, the difference simply reflected the families' needs. The management committee, with the support of the nursing service representative, approved care helpers administering drugs under the direction of the family and the organiser, if that was required when the carer was receiving a break. Purely social/support visits were made to four carers during the 1986 survey week. Two carers had recently been bereaved; in one case the dependant had been admitted to hospital and in the fourth case the carer used the support to talk through worries with the care helper rather than leaving the house.

Tables 5.13 and 5.14 refer to the families in the survey, showing the incidence of disabling conditions and the dependent persons' capacity for self care. The proportion of people helped in each of the selected survey weeks <sup>who</sup> were unable to care for themselves in any way is higher than in the total number considered over two years. This reflects the regular support these families required.

The proportion of dependants suffering from senile dementia in 1986 was slightly less (26%) than in 1985 (36%) and those suffering from neurological disorders and disabilities present at birth slightly higher (50% compared with 41%). These differences reflect the age spread of dependants cared for in the selected survey weeks.

Using the broad self care categories referred to earlier, the two groups of disabled people are seen to have been a little more capable of self care in 1986. This reflects those younger disabled people capable of one or more items of self care but requiring supervision.

TABLE 5.13

DISABLING CONDITION OF DEPENDANTS VISITED IN SURVEY WEEKS

	<u>1985 Survey Week</u>	<u>1986 Survey Week</u>
	*no.	*no.
Arthritis	3	1
Cardio Vascular	4	6
Neurological disorders	8	7
Present at birth	9	10
Accident/disease	2	2
Senile dementia	16	10
General frailty	1	1
<b>TOTAL</b>	<b>43 families (41 disabled people)</b>	<b>37 families (34 disabled people)</b>

\*no. refer to families visited in each survey week. In 1985 and again in 1986 families received support visits after the dependant had died or had been admitted to hospital, (accounted for by difference between total numbers of families and disabled people in brackets).

TABLE 5.14SELF CARE CAPACITY OF DEPENDANTS VISITED IN SURVEY WEEKS

Self care category	<u>1985 Survey Week</u>		<u>1986 Survey Week</u>	
	no.	%	no.	%
Category 1 - Capable of no self care	16	39	13	38
Category 2 - Capable of 1 item of self care	18	44	12	35
Category 3 - Capable of 2 items of self care	7	17	6	18
Category 4 - Capable of all items of self care with supervision	-	-	3	9
<b>TOTALS</b>	<b>41</b>	<b>100</b>	<b>34</b>	<b>100</b>

### Pattern of Support

The pattern of care worked out between carer, the disabled person and the organiser is not a static, inflexible arrangement. The service responded to two of the variables in the caring situation, the health and the well being of dependant and carer. When carers saw themselves as deserving of support they began to ask for more help and at this point the service had been accepted by the consumers and the demand was an indicator of its appropriateness for families.

Most carers need a regular break although this does not necessarily have to be for many hours at a time. As a study of Crossroads Care Attendant Schemes in Essex concluded:

"The sense of relief found in knowing that he or she is not alone in caring is such that even relatively small amounts of the right help have a massive impact on the ability to keep going."

(Audit Commission 1986)

Forty two percent (68:153) of all families felt one visit from a care helper each week was as much relief as they required.

In the 1985 selected week, 141 hours of care were provided by eight care helpers and a further 15 hours by the organiser and senior care visitor. Forty (93%) of the 43 families received regular weekly support.

In the 1986 selected week 134 hours of care were provided by eight care helpers and the organiser and senior care visitor provided a further nine hours. All of the 37 families were receiving regular weekly



support. The lower total care hours in 1986 is accounted for by two cancelled calls and greater travel time. The latter is a reflection of the increase in short visits to get people up or put them to bed. The total number of individual visits to families in each of the weeks were very close - 75 in 1985 and 76 in 1986 (see Appendices for hours of care over two years).

The maximum number of hours allocated to a single family in the 1986 week was 20. This support continued for six months and involved a care helper staying overnight, twice a week with a motor neurone disease sufferer. Four families were allocated between six and eight hours a week over two or three visits. The majority (27) had up to four hours, usually in one visit, although in three cases where the task was to put a disabled person to bed or get them up, up to eight weekly visits were made. The difference between the two years is slight but the overnight support used most of the available hours of one care helper in 1986 thus reducing the allocation options for the organiser.

Table 5.15 shows the pattern of respite care for all the families supported during the scheme. Visits twice or three times a week were arranged with 63 (41%) of families. The occasional help could be all day cover to allow a carer to go away or meet a work crisis.

The input into nine families was frequent, five to seven times a week for less than an hour on each visit and for a specific task. Included here are two disabled people with no carer who also had this level of support. Four of the disabled people were regularly put to bed giving physical relief to the carer. Three elderly people lived alone and

TABLE 5.15

PATTERN OF RESPITE CARE FOR ALL FAMILIES DURING THE STUDY

RELATIONSHIP OF CARER TO DEPENDANT	FREQUENCY OF INPUT				TOTALS
	Occasional	Once a week	2-3 times a week	4 or more times a week	
Daughter	2	22	14	1	39
Son	1	3	6	1	11
Wife	5	14	14	1	34
Husband	-	9	17	3	29
Parent	7	11	4	-	22
Sibling	-	6	6	-	12
Neice	-	2	1	-	3
Neighbour	-	1	1	1	3
<b>Total Families</b>	<b>15</b>	<b>68</b>	<b>63</b>	<b>7</b>	<b>153*</b>

\*In addition two disabled people with no carer had visits more than four times a week.

here the relief for one of the carers (a daughter) was temporary while she was on holiday; in one case the carer's son was working and in another situation the carer was a neighbour who was unwell.

The more noticeable difference between the two selected weeks is in the time of day that support was provided. In February 1985 only 22 hours respite care was given after 6 p.m. or before 8 a.m. out of 156 hours (14%) compared with 69 hours during the same periods in 1986 out of a total of 142 hours (49%). The overnight care influenced the percentage but regardless of that there was a marked shift towards support at anti-social times as a further eight hours were also provided during the day-time at weekends. It was felt in the first year of operation that carers might be more inclined to go out in the summer evenings and there was a rise in evening cover of 30 per cent in August 1985 compared with February of that year. However it seems probable that the time of year is less likely to be the variable than the other commitments of the carer and the family composition.

Sufficient flexibility was built into the timetable of visits to allow for alterations, either pre-arranged or spontaneous and as the care helpers' response to a particular situation. In the 1985 selected week 14 families (33%) received the hours planned by the organiser, 17 families (40%) had more help from the care helpers and 12 families (28%) less than anticipated. The latter primarily reflected people going into hospital and a sudden illness of a care helper. Those families receiving over and above the allocated time benefitted from care helpers extending their stay for social reasons except in two cases where the dependant was ill and needed extra help. The pattern was similar in 1986.

Occasionally carers did not return home at the agreed time. This created difficulties for care helpers who had a visit to make to another family.

### Priority Families

In each of the two selected weeks the organiser was asked to complete an information sheet (Appendix 10) indicating the hours of respite care to be provided, the number of visits and the expected type of care. The organiser was also asked to consider the level of priority (priority, group 1 or group 2) she would give each family if more resources were available taking account of the families' likely response to such an offer. These were judgements the organiser made on the basis of her knowledge of the health and well-being of the carer and the existing support for the family. Table 5.16 shows the priority the same organiser was giving to the families visited in the two selected survey weeks.

Fifty one per cent (22:43) of the families visited in the 1985 selected week were over 70 years of age and nearly half of those (10) were in the organiser's 'top priority' category. Of the families visited in the 1986 survey week 45 per cent (17:37) were aged over 70 years and just over half (6) were in the organiser's 'top priority' (group 1) category. The proportion of families visited in each selected week who were 'top priority' was similar (39 per cent in 1985 and 40 per cent in 1986). It is unlikely that the organiser's assessment procedure altered radically, although it will have been refined with experience, but there was a slight difference between the two groups of families

TABLE 5.16

FAMILIES VISITED IN 1985 AND 1986 SELECTED WEEKS BY ORGANISER'S PRIORITYCATEGORY\* AND AGE OF DEPENDANT

Age of dependants in years	1985	Priority Group 1	Priority Group 2	1986	Priority Group 1	Priority Group 2
0-19	6	3	3	3	3	1
20-29	2	-	1	2	1	1
30-39	5	1	2	4	2	1
40-49	2	1	-	4	2	1
50-59	3	2	-	4	-	2
60-69	3	-	2	3	1	2
70-79	14	8	5	10	3	7
80+	8	2	5	7	3	-
<b>**TOTALS</b>	<b>43</b>	<b>17</b>	<b>18</b>	<b>37</b>	<b>15</b>	<b>15</b>

\*Priority categories refer to the Organiser's assessment of the families need for respite care and the level of priority given to those families if additional resources were available (see page 87).

\*\*Eight families in the 1985 selected week and seven families in the 1986 survey week were not given a priority category because:

- (a) carers were not in need of further support;
- (b) domiciliary respite care was inappropriate;
- (c) dependant had died or was in hospital and the carer was receiving support visits.

visited with a greater need being identified in the younger age group in 1986, although the percentage of people on the monthly caseload over 70 years was the same (50%).

#### Duration and Outcome of Support

After the initial build up period of three months there was a monthly caseload of 55-65 families receiving support. Fig. 5.3 shows the case load over the two years. The change of clients can be seen more easily when the losses are examined. During the course of the study period contact ceased with 95 (59%) of the 159 disabled people and their carers who were supported.

Tables (5.17 and 5.18) show the duration of care provision.

#### Death

Deaths were the cause of terminating the contact within three months in the case of half the families. Sometimes the involvement of the service was minimal but with other families the support was three to four times weekly and involved up to eight hours respite care a week. In many cases the contact continued informally with the care helper attending the funeral and the organiser making an occasional support visit.

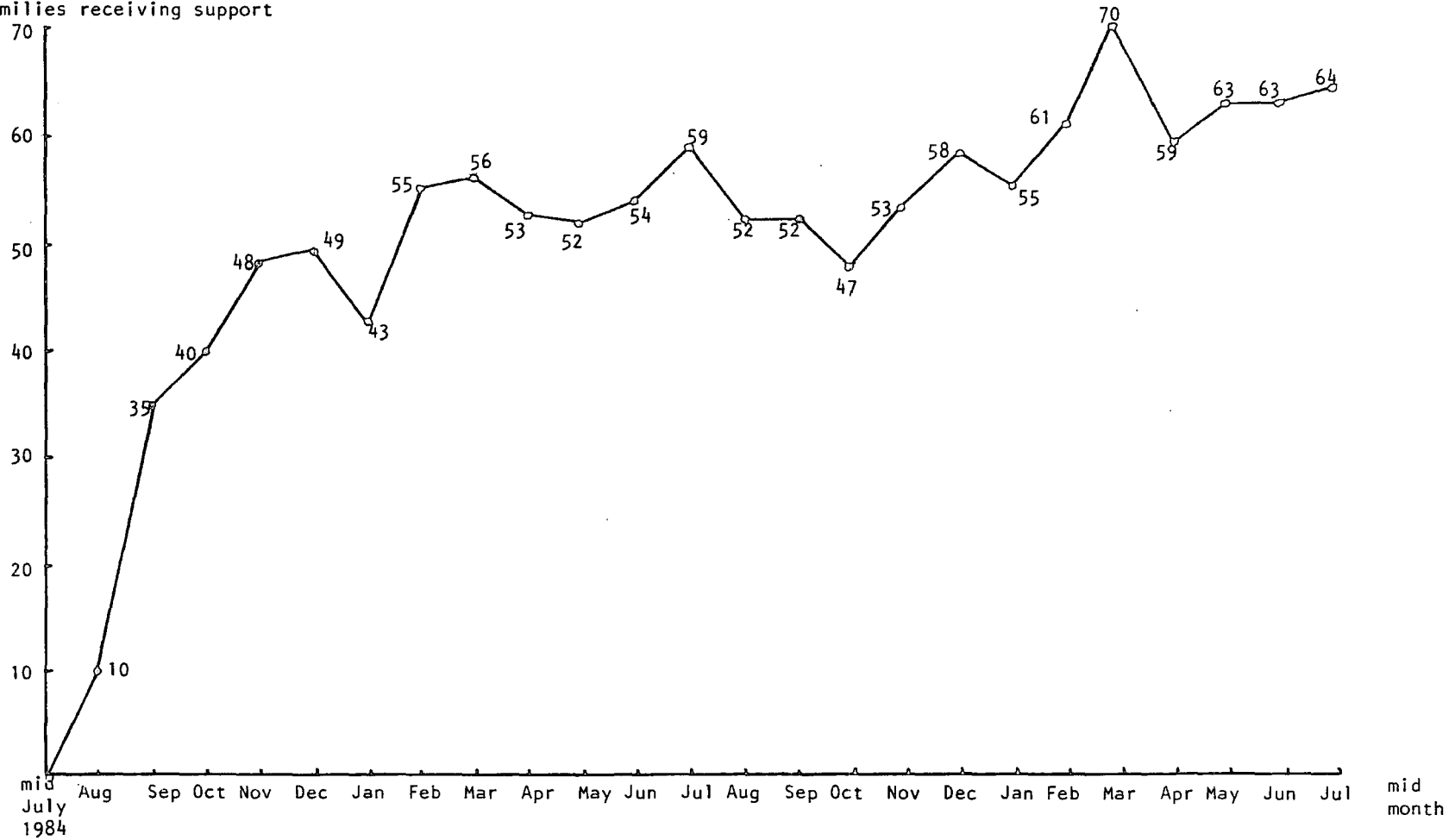
#### Admission to institutional care

Twenty one disabled people were admitted to institutional care during the course of the study, this group was elderly with the exception of a

Figure 5.3

CASE LOADS July 1984 - July 1986

\*Numbers of families receiving support



\*Figures taken from 28 day returns presented to Management Committee meetings

TABLE 5.17DURATION OF CARE

<u>Duration of Care</u> <u>(at end of contact)</u>	<u>Disabled People</u> <u>No.</u>
Up to 3 months	41
Up to 6 months	25
Up to 9 months	10
Up to 1 year	9
Up to 15 months	4
Up to 18 months	2
Up to 21 months	2
Up to 24 months	2
<hr/>	
TOTAL	95
<hr/>	

TABLE 5.18REASONS FOR ENDING CARE

	<u>Disabled People</u> <u>No.</u>
Death of disabled person	40
Admission to insitituion	21
Recovery	4
Other	30
<hr/>	
TOTAL	95
<hr/>	



young multiple sclerosis sufferer. In three cases the person was terminally ill or re-admitted to hospital after a short period at home. Of the remainder, two couples became too frail to be safely left alone at home as their carers were non-resident. They were admitted separately to a nursing home and hospital. Twelve of the remainder were admitted to hospital psycho-geriatric or long-stay wards. Half of those people who eventually left their homes for institutions had been supported by Durham Community Care helpers for more than six months. Six dependants were living with their carer and four lived separately. It is impossible to say categorically that earlier admission to an institution would have been the outcome for dependants without the intervention of Durham Community Care but it is reasonable to assume that supporting them helped reduce the strain on families and eased the admission to care of highly dependent people.

### Recovery

Four disabled people required support temporarily after surgery and recovered sufficiently for their carers to no longer require help.

### Other reasons for ending care

The 30 dependants with whom contact ceased for other reasons warrants some investigation (see Table 5.19). Sixty per cent (21:30) had been in contact with Durham Community Care for up to three months and the majority of them had been accepted on a temporary basis until alterations to property had been carried out, children were in full-time school or alternative private help had been found. However, in the first three months of contact, four families felt unable to

TABLE 5.19

TERMINATION OF CONTACT WITH FAMILIES DUE TO REASONS OTHER THAN DEATH,  
ADMISSION TO INSTITUTIONS OR RECOVERY

	<u>No.</u>
Change of Carer situation, e.g. holiday/work/support	4
Change in dependant's needs, e.g. health deteriorated	2
Private help arranged	2
Temporary transport no longer required	2
Children started full time schooling	4
Other domiciliary services more appropriate	3
Alterations to accommodation removed problems	4
Care helper left and continued contact voluntarily	1
Moved away	4
Changed mind about accepting care help	4
<hr/>	
TOTAL	30
<hr/>	

continue to receive a care helper. In each case the disabled person was elderly and in three cases suffering from senile dementia. The carers felt unable to cope with the change of routine and although the numbers are small it illustrates the fact that pressure on carers is often so high that however desperately needed a break may be, from the point of view of the observer, coping with a change may be too difficult for the carer her/himself.

Of the eight families whose contact ceased after more than three months four moved away, two received the adaptations/equipment they required to function without help - a stair lift and a hoist - one child started school and in the remaining case the daughter carer was made redundant from work and no longer required the specific day-time cover which had been provided for her mother.

### Long Term Families

Of the survey families who were receiving domiciliary respite care in February 1985, 15 were still being visited in 1986 and formed 40 percent of the second weeks' case load. The organiser's priority category (Table 5.16) for these families showed some changes and these modifications were due firstly to the physical well-being of the dependant and the carer and secondly to the attitude of the carer to the level of support being provided. In three of the 15 cases the priority category was inappropriate as one dependant had died and two were in long term hospital care. The two elderly gentlemen in hospital continued to be visited until the care helpers left and were replaced leaving no one working for Durham Community Care whom they would recognise.

In four cases there was no change in the dependency level of the disabled person or the caring ability of the carer. Two were young disabled people with non-degenerative disorders and the others, although they had deteriorated physically during the twelve months, were not requiring substantially more care.

The organiser considered two families to be a lower priority in 1986 than 1985. One dependant was capable of one item on the self care scale (feeding) and the other needed total care but their carers were satisfied with the support offered and unwilling to accept any more. In the remaining six families a deterioration in the physical health of both dependant and carer caused the organiser to feel they would benefit from more support if it was available.

The pattern of support for the families receiving visits during both years changed. In one case a multiple sclerosis sufferer had become so ill he could no longer be taken out or have his hair washed but the rest of the disabled people received more personal care and in three cases the number of visits per week was increased from two to between six and eight, to assist with bedtime and getting a relative up and toiletted.

It was possible to point to a core of families who required long-term support and envisage continuing to require such support. Twenty two families had received help for more than 12 months and eight of these were involved since the start of the scheme. Half of these core families had a disabled member under 50 years of age and for eight of them their disabilities were such that they were expected to remain in

a fairly stable condition for some years. The remainder suffered from degenerative diseases expected to reduce their very low levels of self care. For all these younger people the care helpers' visits became part of their expectations, particularly for those whose carers had weekly respite.

### THE CARE HELPERS

During the two year project 20 part-time and two full-time care helpers and an organiser were employed by the scheme. The care helpers were employed on 12 month non-renewable contracts after a three month probationary period. The organiser's contract was renewable. When she resigned two months before the end of the project the senior care helper was appointed in her stead. The only male staff member was the senior care helper employed in the first year.

The care helpers ranged in age from 18 years to 59 years with the majority in their 30s and 40s. Their work and their personal experience were equally varied although half had nursing training to some level or had worked in a formal caring setting as a volunteer. Most of the care helpers would have preferred to continue working in the community had their jobs with Durham Community Care been secure.

The aims of the Manpower Services Commission were achieved in ten cases where care helpers obtained permanent employment on leaving, eight of these in nursing or auxiliary posts. Three staff were employed by Durham Community Care on a temporary basis to assist with training new care helpers and ease the change over period at the end of each year.

Qualities of tolerance, patience, resourcefulness, sensitivity and practical good sense are required by care helpers. They must be honest and reliable and enjoy caring for people. The management committee was careful in the choice of its staff.

### Training

A comprehensive training programme (see Appendix 17) was followed before care helpers undertook any caring responsibilities and ongoing training and supervision continued in regular review sessions with the organiser. Care helpers were expected to participate fully in discussion groups and work allocation meetings\*. Care helpers found the choice of programmes both of immediate use, particularly the First Aid courses, and helpful as they became more experienced and could use information, for example, on welfare benefits and allowances and available aids and adaptations.

The wide range of academic abilities of care helpers presented some problems in training on a programme which included a number of lectures. They generally found practical sessions the most helpful part of the training but identified a need for more knowledge of bereavement counselling. They felt sessions designed to raise the care helpers' consciousness of the experience of handicap and caring were particularly helpful.

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\* Care helpers' work commitments varied weekly and each worker was responsible for checking their diary with a master diary kept by the organiser (see Appendix 18).

### Allocation of Families to Care Helpers

Care helpers usually stayed with the same families. More than one care helper was introduced if possible to ensure that families did not have to accept strangers in the event of sickness or holidays. The organiser aimed to match personalities and interests of family and dependant with the proposed care helper. If there was a miss-match, both family and care helper were encouraged to discuss this and a change of staff was arranged. The care helper was shown how to work with the dependent person, by the family carer. This established confidence on all sides.

A small percentage of families were always visited by more than one care helper at a time. This was where the dependant was physically too heavy or difficult to be managed alone.

Although cognizant of the conditions of their employment at the outset the majority of care helpers were distressed to have to leave at the end of 12 months. Only four left of their own volition before the end of their contract and each went into full time employment in the field of nursing.

## CHAPTER 6

### FINDINGS: A DESCRIPTION OF THE FAMILIES

#### INTRODUCTION

There are an estimated 1,500,000 carers nationally and 80,000 in the North East of England (Association of Carers Press release May 1st 1985). The Durham Community Care catchment area, therefore, may contain as many as 2,000 carers.

The door to door survey of carers carried out in two small areas of Durham, achieving a 75% contact rate (186 out of 249 households) revealed 21% of respondents had current or recent (within past 5 years) direct caring experience. Twenty people (13%) identified themselves as currently caring for a relative who was dependent on them and 14 carers (7.8%) described their lives as restricted by their responsibility for a dependent person. Interviews with the 20 carers revealed five people (3%) who were providing substantial care for a relative. Their circumstances met the criteria used by the organiser of Durham Community Care when offering respite care. The figures support projected estimates of the numbers of carers but only a small proportion were reached by the scheme.



This chapter introduces the 153 carers and 159 dependants supported by Durham Community Care during the study and makes reference to the door to door survey findings.

### THE CARERS

One hundred and eleven main carers were women and 42 were men. This ratio supports other work which shows that carers are most likely to be female (Hunt 1968, 1978, Blaxter 1977, Briggs 1983, Oliver 1983, Finch 1987). The door to door survey revealed 12 female and two male carers whose lives were restricted by caring. The social expectations and the family patterns in western society, in this century, manoeuvre women into caring roles (Graham 1983). Images of self and 'ideal' family units are reinforced by stated government philosophies (DHSS 1981) and uncertain economic opportunities for women, even in the widening part-time labour market, encourage the domiciliary care option as the answer to looking after a relative in need. (Nissel and Bonnerjea 1982, Ungerson 1983).

Women come to care via a variety of routes and their attitudes towards their responsibilities are sometimes seen in terms of altruism - regard for others as the motivation for action (Sussman 1965), reciprocity - action as a return for past services (Abrams & Marsden 1985) and obligation - a sense of moral compulsion to care for kin (Finch 1987).

Many people, however, care through devotion where the boundaries of obligation are narrow, but intensely felt, because they are based on personal relationships (Pinker 1985). Such kinship bonds which are the basis of care for severely handicapped people cannot involve concepts

of reciprocity (Borsay 1986) but are cultural expectations reinforced by social pressure and are rarely conflict free (Shanus et al 1981).

The interviews carried out in this study bore out the complexity of drives and unavoidable circumstances which bring women to care.

Table 6.1 reflects the primary carer in each household, it shows that women outnumbered men by about three to one. Some men perform a greater role as carers than others and women carry the bulk of the responsibility for their disabled child (Hewitt 1970, Wilkin 1979, Glendinning 1983). There were only a small number of families with disabled children in this study (19:153). However, while highlighting the physical/lifting help fathers provide, the investigation produced no indication that there is any overall change in responsibilities within families. For that reason where two parents are caring for a handicapped child the mother appears in the figures as the primary carer.

Men come into their own when looking after the 70 plus age group. Forty four carers in this study were over the age of 70 years (44:153) and nearly half of them (20:44) were men.

### Age of Carers

Carers varied widely in age. The youngest carer in this study was a 21 year old woman living alone with her seriously confused grandmother. The oldest, a blind husband of 92 years caring for his arthritic wife who was also suffering from Alzheimer's disease.

TABLE 6.1CARERS BY AGE AND GENDER

<u>Age</u>	<u>Male</u>	<u>Female</u>	<u>Totals</u>
	<u>No.</u>	<u>No.</u>	<u>No.</u>
20-29	-	6	6
30-39	1	13	14
40-49	5	25	30
50-59	8	28	36
60-69	8	15	23
70-79	16	24	40
80-89	2	-	2
90+	2	-	2
<hr/>			
TOTAL	42	111	153
<hr/>			

The term 'mediatric' has been borrowed from Cantrell et al (1985). In the present study the term has been used to describe people aged between 20 years and 69 years. This broad age band was chosen because it reflects the period of life when people might expect to shoulder, and enjoy, responsibilities of work and family and lead active lives. Cantrell has a cut off point of 65 years, for his 'mediatric' group in common with most age related statistics which describe 'old age' as beginning with entitlement to state benefit, but some argue in favour of 70 years of age for such a description (Abrams, 1981) believing it is a more helpful chronological definition for health statistics, in particular, because it represents the point at which most people have a life expectancy of about ten years.

Consistent with many other investigations (Tizard & Grad 1961, Hunt 1968, Bayley 1973, Nissel & Bonnerjea 1982, Glendinning 1983, Charlesworth et al 1984, Wright 1986), this study found that over half the primary carers were aged between 40 and 69 years (55% 89:153). Over two thirds (68:153) of these were women.

Forty (40:153) carers were aged between 70 and 79 years. Other studies have revealed similar findings (Cartwright 1973; Wilkes 1973, Charlesworth et al 1984).

#### RELATIONSHIP OF CARER TO DEPENDANT

Given that caring is a predominantly female activity, the relationship of carer and dependant throws some light on the circumstances which make women carers. Charlesworth et al found a high proportion of

husbands over the age of 70 who were carers, but also found a gender pattern which they describe as:

"... quite striking. Seventy per cent of elderly men were cared for by male relatives, mostly sons and seventy three per cent of women by female relatives mostly daughters."

(Charlesworth et al, EOC 1984, p. 11)

Although in the present study a gender pattern can be recognised amongst the large total of females in the study, 65 of all 111 female carers cared for a female dependant, the pattern is less discernable amongst the males even when considering only elderly dependants. Four of the 11 sons were caring for fathers but no other male carer/dependant relationships were encountered. Charlesworth et al drew their observations from elderly people who had been referred for specialist services and thus excluded carers who received no statutory care.

Table 6.2 shows the relationship of carers and dependants in the study and indicates the generations to which they belong. This form of presentation was chosen also for Tables 6.3 and 6.4 encompassing the possible relationships within the caring situation and the age of the carer.

Similar numbers of carers were looking after dependants of the same generation (72:153) as were caring for the generation older than themselves (62:153) but women predominate (51:11) when taking over responsibility for their parents' generation. The only neighbours (3:153) who figured were female and caring for an elderly person

TABLE 6.2

THE RELATIONSHIP OF CARER AND DEPENDANT BY GENDER

	Generation of Carer in relationship to Dependant*			
	Younger	Same	Older	Total Carers
	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>No.</u>
Female Carer. Female dependant	45	7	13(+1)	65
Female Carer. Male dependant	6	34	6	46
Male Carer. Female dependant	7(+3)	31		38
Male Carer. Male dependant	4			4
<b>TOTAL</b>	<b>62</b>	<b>72</b>	<b>19</b>	<b>153**</b>

\*Dependants n = 159

(2 dependant people, both female, had no carer)

\*\*3 sons supported both parents

1 woman supported her mother and disabled daughter

These 4 dependants appear as the bracketted figures.

TABLE 6.3

GENDER AND GENERATION OF CARERS IN RELATION TO DEPENDANT

	Gender of Carer		Relationship to Dependant	
	Male	Female		
Carers caring for older dependants n = 62	11	51	11 sons	45 daughters 1 granddaughter 3 neighbours 2 nieces
Carers caring for dependants of same generation n = 72	31	41	29 husbands 2 brothers	32 wives 9 sisters
Carers caring for dependants of younger generation n = 19	-	19	11 parents sharing care with mother primarily responsible. 8 lone mothers.	
<b>TOTALS</b>	<b>42</b>	<b>111</b>		

TABLE 6.4

RELATIONSHIP OF CARERS AND DEPENDANTS BY AGE AND GENERATION

Age of carers	Men caring for dependants of same generation	Men caring for older dependants	Women caring for dependants of same generation	Women caring for older dependants	Women caring for younger dependants	Total male carers	Total female carers	Total carers
	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>No.</u>
10-19								
20-29	-	-	-	2	4	-	6	6
30-39	1	-	4	4	5	1	13	14
40-49	1	4	2	16	7	5	25	30
50-59	2	6	6	21	1	8	28	36
60-69	7	1	7	7	1	8	15	23
70-79	16	-	22	1	1	16	24	40
80-89	2	-	-	-	-	2	-	2
90+	2	-	-	-	-	2	-	2
<b>TOTALS</b>	<b>31</b>	<b>11</b>	<b>41</b>	<b>51</b>	<b>19</b>	<b>42</b>	<b>111</b>	<b>153</b>



much older than themselves. In the door to door survey one female neighbour was identified helping an older person.

### Siblings

Sisters (9:153) and brothers (2:153) cared for siblings. Both brothers were caring for disabled sisters. Nine of the 11 sibling caring relationships occurred in the oldest carer group of 70 years and over (Table 6.4). Those carers were predominantly unmarried or widowed sisters who rarely questioned their responsibilities.

"Me father had always looked after her and when he died it was obvious she had to come with me. I mean I couldn't put her away could I?"

"I had to bring her home (from America). We had always been a close family and I couldn't have rested wondering what would happen to her. Our parents brought us up to care for each other."

One brother found his caring position unacceptable. His sister had come to housekeep for him when their parents had died but became crippled with arthritis.

"It's not right. You shouldn't expect a man to do that sort of thing (toileting). I never had to do any housework either when me mother was alive."

### Parents

Fathers cared for their disabled children but, without exception, those fathers who were working (10:11), took a secondary role in the care of their child (Hewitt 1970). One father was retired and in ill health

but still provided physical care for his 35 year old son who had cerebral palsy.

The 'muscle power' that fathers could provide was often remarked upon by mothers who had difficulty moving their children when the fathers were at work. Glendinning notes that it is not so much what fathers do but:

"... their perceived willingness to share the 'daily grind' which affects the level of stress in the family".

(Glendinning 1983)

It has been widely observed that the 'daily grind' (Bayley 1973) of caring for a disabled person can create pressures on a marriage (Bayley 1973, Wilkin 1979, Glendinning 1983, Baldwin 1985). It is noteworthy that eight (8:19) of the mothers in this study were caring alone. One of these mothers was widowed but clearly some marriages do not survive such pressures.

### Sons and Daughters

Sons who were primary carers (11) were generally well supported by their female relatives, usually their wives. In only four cases were sons shouldering the main caring responsibilities and in the absence of female relatives statutory help was offered to them.

Married sons without sisters experienced role conflict and the degree to which they supported their parents was the measure of the strength of the marital sanction or encouragement to do so.

The elderly couples who have both grown infirm are an increasing section of the ageing population and their care needs require a wide range of options to be available, including relief for the most able partner. When a daughter lives nearby she may provide much of that relief (Wenger 1984). Married daughters and daughters-in-law comprised 9 of the 12 female carers identified in the small door to door survey, and noticeably two thirds (6:9) were caring for parents not living with them.

Unmarried daughters in their 50s and younger are declining in numbers. Today their proportion against married women is one in 14 compared with one in six, 50 years ago (OPCS 1980). The reduction of this natural caring population of unmarried daughters has implications not only for their elderly parents but for their married siblings. The carers who have responsibilities beyond those to their infirm dependants are growing in number as married women become primary carers to elderly parents. These care givers to more than one generation are often those offered least support by statutory authorities (see Chapter 8).

The steady rise in the number of old people in the community will raise the average age of the children who care for them and retired people caring for the generation above them will be increasingly familiar (see Table 6.4). In the lone carer/dependant households (72:153) 15 carers (21% 15:72) were looking after a parent. Half of these (8:15) were in the 40-59 years age group. When carers had additional responsibilities of family and work (54:153) almost half (25:54) were caring for their parents and were in the 40-59 years age groups. These middle-aged

women, described by Brody (1981) as 'Women in the Middle' outnumbered men as carers four to one (53:13).

Divorcees did not figure greatly in the groups caring for those of the same generation or above but the four divorcees caring for parents were doing so primarily because their siblings had 'family responsibilities'. One sister found herself in the same position assuming the caring role for a mentally handicapped woman after the death of their parents.

Divorce and remarriage blur the lines of responsibility towards parents (Parker 1985). Divorce without remarriage may make caring for a parent economically impossible but it could become more socially desirable as it provides companionship (Wicks 1982, Grey 1983). Some of the future divorced and unsupported elderly people, therefore, may have been carers of their own parents. They could be in the position of the single carer (Wright 1986) who is shouldering responsibility because he or she has remained unmarried.

In the light also of smaller families and the rising number of divorces between couples with no dependent children that make up half of all divorces (EOC 1986) it may be fruitful to explore the expectations placed on divorcees to care for their elderly relatives in the context of the help they might expect in their own old age.

### Spouses

Husbands formed the majority of male carers in the study (see Table 6.4 p.142) (29:42) and both of the male carers in the door to door survey.

Most (19:29) were aged over 70 years and it is possible that the greater mobility or mental agility of one partner was all that determined who was designated the carer (Cresswell and Pasker 1972).

Of the 32 wives, nine were under 60 years of age. Most were caring for husbands who were suffering from degenerative diseases and required high levels of personal care.

### Secondary carers

The relatives, children or parents who live with main carers and their dependants and share the caring tasks can be described as secondary carers. When more than two generations live together secondary caring is inevitable, particularly for grandchildren of elderly infirm people. Where a young parent needs care children invariably take on a minor caring role, even if merely supervisory.

### HOUSEHOLD COMPOSITION

The household composition of disabled and carer provided the setting for the relationships of dependants and carers. Other researchers have simplified their field by concentrating on a particular target group of dependants, for example children (Glendinning 1983, Baldwin 1985) or carers, such as lone daughters and sons (Wright 1986). These investigations are highly relevant for policy makers because the needs of a specific population are explored in detail. The current study, however, could not be so selective as its purpose was to examine the performance of a service which included in its remit carers of dependants of all ages and all disabilities, with the exception of the

mentally ill. Carers are not a homogeneous group but they do have common experiences regardless of the relationship to their dependant. The complexity of the caring relationships, which becomes apparent when the composition of the households is considered, is of central importance in the dynamics of caring. Table 6.5 shows the household composition encountered in the study.

Twenty five dependants were living away from their carer and all but one of those were over 70 years of age and looked after by a younger relative.

Twenty eight infirm elderly people relied on their sons, daughters, nieces or neighbours for daily care. For the care givers non-residency adds additional elements of worry to the responsibilities of care, with frequent visits to be fitted into a daily routine. Consistent with other findings non-residency did not appear to affect the level of care given to the dependent people (Wade et al 1984, Wenger 1984). However, distance undoubtedly makes care giving more difficult and increases anxiety as the following comments of two non-resident carers illustrate:

"Sometimes I was down there four and five times a day. You'd never know what you might find. I was afraid to open the front door sometimes."

"At first it was the shopping and the washing. Well that's alright, going in two or three times a week to see they were OK but when she got really bad me dad didn't know what to do and kept ringing me, so now I go in every day first thing, at dinner time and in the evening. The problem is the buses you never know when they're coming and it can take ages. But he's happier."

TABLE 6.5HOUSEHOLD COMPOSITION AND DISABLED PERSON

<u>Household Composition</u>	<u>Disabled people</u>
	<u>No.</u>
Couples (one carer)	46
Dependant living alone with non-resident carer	25
Family with children under 16 years of age; dependent child or parent	24
Three generations, dependent grandparent	16
Adult child and dependent parent	15
Married couple and dependent parent	12
Siblings (one carer)	8
Family with adult child at home and one dependant relative	4
Dependent couple with non-resident carer	4
Elderly parent and dependent child	3
Living alone with no main carer	2
<hr/>	
TOTAL	159
<hr/>	

Although the examples above are of the pressure on daughters, it was sons who were most likely to be non-resident. Daughters almost invariably brought a parent or parents to live with their own families. Of the 12 dependent parents living with married couples 11 were living with daughters.

The three generation households comprised 16 daughters caring for a disabled parent(s). or parent(s)-in-law (one) with the additional responsibility of their own children. These female carers expressed particular anxiety about the adverse affect on their children of the restrictions on the family caused by an elderly or infirm relative in the home ... "The children don't like to bring their friends home" or "The children's activities had to revolve around my mother's needs" were typical reactions of these 'women in the middle' (Brody 1981).

Children were often a great deal of help to their mothers in caring for elderly parents as Glendinning (1983) discusses and their 'secondary care' was appreciated. However, the conflict daughters, in particular, felt when looking after a parent and their own family, ironically could be exacerbated by a child who shared no resentment for the grandparent. One married women with two children of 15 years and six years had the care of her severely demented mother. She relied on her daughter's help but worried about the effect on her schooling.

"She (daughter) is good with her, she can put her to bed herself and she's got endless patience. She does voluntary work at St. Mary's (local geriatric hospital). I think it does affect her, though she doesn't admit it, as she had appalling exam results at Christmas .. at that time she (grandmother) was screaming all the time. Miranda's nowhere else to work except in here".



Nevertheless, the very presence of children is probably a further reason for women caring for elderly parents in their home. The logistics of running two homes become impossible.

"Well, I had to have her. When me father died Paul was only a year and ten months old so I couldn't be going there three to four times a day so she had to come to me ... I couldn't cope with her up there and me here".

Of the nine non-elderly wives caring for their husbands all but one also had the responsibility of children. These wives were under extreme pressure, living in accommodation often unsuited to the differing needs of a disabled person and children and receiving little formal support from caring agencies.

#### THE CHARACTERISTICS OF DEPENDANTS

Stephenson, in her discussion of caring and dependency rightly reminds us that:

"..... there is no moral judgement inherent in the words 'independent' and 'dependent'".

(Stephenson, 1981, p. 128)

The noun 'dependant' is used in this study to indicate a person who is reliant on another for help with daily living. The fact that the resulting interdependence of individuals is complex emotionally, and extends into other areas of their lives is central to the investigation.

Tables 6.2 and 6.3 showed the sex of dependants and carers and their relationship to each other. Female dependants outnumbered males two to one (107:50).\* Forty two per cent of female dependants (45:107) were cared for by women younger than themselves usually daughters and 29 per cent (31:107) by their husbands. Sixty eight per cent of male dependants (34:50) were cared for by their wives. Dependants ranged in age from three to 93 years old with 64 per cent (101:56) over 70 years of age.

The wide distribution of the age of dependants suggests that they will have an equally wide range of needs. The personal and social needs of someone of 70 years will be different from someone of 17 years. The personal care requirements, however, are closely tied to the cause of disability in an individual. Someone of 50 years who has suffered a spinal injury for example, may require a high level of intimate personal care if paralysed from the waist down but be capable of keeping an outside job and running a home. A person only ten years older suffering from Alzheimer's disease might require 24 hours a day supervision and be quite incapable of any aspect of self care.

The World Health Organisation (1980, p. 29) defined 'impairment' as "any loss or abnormality of psychological, physiological, or anatomical structure or function". A 'disability' was defined as "any restriction or lack (resulting from impairment) of ability to perform the activity in the manner or within the range considered normal for a human being". Handicap is defined as "a disadvantage for a given individual resulting from an impairment or a disability that limits or prevents the

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\*Two dependent people (both female) had no carer.

fulfilment of a role that is normal for that individual".

Borsay (1986) uses the terms impairment, handicap and disability interchangeably. She does this because she recognises the confusion over terminology in the field and that physical environment effects the level of support people with similar impairments may require. While basically sharing this view point there is an attempt in this thesis to respond to the carers' perspective and in doing so the language used by the individual affected must be acknowledged. The principles of normalisation ( Wolfensberger 1972) are held deeply by some families who feel handicapped by others' attitudes. Some attempt has been made therefore to distinguish between impairment as a loss or 'abnormality' and 'disability' and 'handicap' as the resultant restriction on activity. The latter two terms have definitional problems and they are used with those problems in mind.

If handicap is defined in terms of the role an individual would normally have carried out if not prevented by impairment or disability problems arise when trying to evaluate a role for people across three generations. There are clear expectations of the responsibilities and activities that could be 'normal' for children and young and middle aged adults but the expectations of old age are less clearly defined; both of the old themselves and of younger people towards them. (Roscow 1974, Townsend 1986).

The controversial 'disengagement' theory of Cummings and Henry (1961) which argues a predictable decline in roles of elderly people as a preparation for the inevitability of death has been widely criticised ( Townsend 1965, Rose 1968, Wright 1986) on the basis of evidence

of an increase in the activities of the elderly and alternative causes for disengagement, for example bereavement.

The norm for old people is therefore difficult to describe and as Wright (1986) argues assessing handicap in WHO terms "remains meaningless for old people". Difficulties of ascribing roles to the elderly arise because of opportunities for diverse activities but no clear guide as to what they should be doing with their time (Roscow 1974).

The employment trends in the 1980's place many people in the position of the elderly. The norm may be full-time employment but the reality may be part-time short-term work at best.

Full-time employment is sought alongside entreaties to early retirement and creative lives following redundancy. The norm for a disabled person whose physical limitation cannot be identified is very vulnerable to the handicapping effect of the attitudes of the general public (Shearer 1979). This may be particularly so when individuals cannot come to terms with reduced opportunities for the physically active population.

#### Reported Causes of Impairment and Disability

The reported causes of the impairment of people being looked after at home were varied. Table 6.6 shows these causes and the number of dependants referred to the scheme over the first two years. Twenty four per cent of all individuals were suffering disability because of some form of senile dementia or Alzheimer's disease. This appears

TABLE 6.6

REPORTED CAUSES OF DISABILITY AND YEAR OF REFERRAL  
OF ALL REFERRALS TO THE SCHEME (n = 208)

<u>Disability</u>	<u>Year 1</u>	<u>Year 2</u>	<u>Totals</u>
	<u>No.</u>	<u>No.</u>	<u>No.</u>
Senile Dementia and Alzheimer's disease	31	18	49
Stroke	19	14	33
General frailty	14	18	32
Multiple & Disseminated Sclerosis	10	4	14
Cancer	4	8	12
Mental & Physical Handicap	6	4	10
Parkinsons's disease	4	4	8
Mental Handicap	5	1	6
Arthritis	2	3	5
Cerebral Palsy	3	2	5
Heart 'Problems'	2	2	4
Post operative debility	2	2	4
Deafness	3	-	3
Down's Syndrome	2	1	3
Paraplegia	3	-	3
Amputation	-	2	2
Cerebral Ataxia	-	2	2
Freidrick's Ataxia	-	2	2
Motor Neurone Disease	-	2	2
Peripheral Neopathy	-	2	2
Spina bifida	2	-	2
Chest 'Problems'	1	-	1
Emphysema	-	1	1
Haemorrhage	-	1	1
Hydrocephalis	1	-	1
Tuberculosis	1	-	1
<b>TOTALS</b>	<b>115</b>	<b>93</b>	<b>208</b>

higher than that of the early Crossroads Schemes, although comparable categories are not used and make comparison difficult, (Bristow 1981). The number of dependent people suffering from senile dementia, together with the other large category of dependants, those suffering from general frailty, reflects the multiple medical problems of the very elderly (Brocklehurst 1981). The predominant condition, however, is that used in the category description and such information was obtained from the case files and in some instances, therefore, is the diagnosis ascribed by the carer.

Table 6.7 gives a picture of the age distribution and conditions causing dependency in the disabled people whose families were supported. Impairments are often related to age in their disabling consequences. As the age distribution of dependants is wide, analysis of impairment and its disabling consequences must be age related. The consequences of the impairment in terms of the degree of disablement is looked at in terms of the extent to which the dependent person is able to manage his/her self care.

### Self Care Abilities

The basis of categorising individuals' dependency in relation to self care was based on their reported ability to carry out activities with or without assistance. These judgements by the carer were agreed in the assessment interview, either confirmed by the dependant (where possible) and/or the organiser's observation. The dependant was present at all initial interviews between carers and the organiser.

TABLE 6.7

DISABLING CONDITION CAUSING DEPENDENCY AND AGE OF DEPENDANTS SUPPORTED (n = 159)

Disabling condition	0-9	10-19	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90+	Totals	%	M.	F.
	No.	No.	No.	No.	No.	No.	No.	No.	No.	No.			No.	No.
Senile dementia/ Alzheimers disease	-	-	-	-	-	-	2	19	17	1	39	25	4	35
Cardio vascular/ respiratory	-	-	-	1	-	-	6	18	8	-	33	21	18	15
Neurological disorder	-	1	1	3	5	4	3	7	-	-	24	15.0	10	14
General frailty	-	-	-	-	-	-	-	4	6	9	19	12.0	5	14
Present at birth	4	6	3	3	1	2	-	-	-	-	19	12.0	6	13
Accident/disease	3	1	-	-	2	1	4	5	1	-	17	11	5	12
Arthritis	-	-	-	-	-	-	-	5	1	-	6	4	-	6
Paraplegia	-	-	-	1	-	-	-	-	-	-	1	1	1	-
Mental illness (temporary care provided)*	1	-	-	-	-	-	-	-	-	-	1	1	1	-
<b>TOTALS</b>	<b>8</b>	<b>8</b>	<b>4</b>	<b>8</b>	<b>8</b>	<b>7</b>	<b>15</b>	<b>58</b>	<b>33</b>	<b>10</b>	<b>159</b>	<b>100</b>	<b>50</b>	<b>109</b>

\*Temporary care was provided for a toddler while his mother attended hospital - ECG treatment.  
This case was not strictly within the remit of the scheme.

The self care tasks were grouped into three areas of activity:

Toileting: bowel and bladder care, and washing but excluding bathing.

Feeding: After food had been prepared.

Mobility: Walking about a room unaided.

Table 6.8 shows the proportion of dependants cared for who were able to carry out self care tasks and those experiencing difficulties in particular categories of self care.

Only six dependants, disabled children and young people with a mental handicap, were able to perform all three tasks or activities of self care without assistance. However all needed supervision in these tasks and were at risk if left unattended.

Those dependent relatives able to manage two self care activities without help were mainly over 60 years of age. About one third of them were suffering from senile dementia or Alzheimer's disease and retained some mobility. All the people who managed two tasks or activities were able to feed themselves provided the food was prepared and put in front of them.

Self-feeding was managed by almost two thirds of all disabled people (65%) and it would appear for the elderly and those suffering from degenerative diseases, it is the skill they retain longest, even if the tasks are performed with some difficulty. Feeding a severely handicapped person is a slow and taxing task demanding time and



TABLE 6.8PROPORTION OF DEPENDANTS ABLE TO CARRY OUT SELF CARE TASKS

	Nos.	%
Category 1 - Able to perform tasks in each self care category without assistance but under supervision	6	4
Category 2 - Able to perform tasks in two self care categories without assistance	37	23
Category 3 - Able to perform tasks in one self care category without assistance	73	46
Category 4 - Unable to perform any self care without assistance	43	27
<hr/>		
TOTALS	159	100%
<hr/>		

patience. It is a task carers were invariably unable to delegate to secondary carers who feared the disabled person might choke or vomit.

No dependant was able to bathe without help or supervision and over one quarter of the disabled people (27%) were unable to feed, toilet/wash themselves or walk even a few steps without assistance. They required total care from another person.

The dynamics of the relationship between the carers and their dependants is explored in Chapter 7.

## CHAPTER 7

### FINDINGS: THE DYNAMICS OF CARING

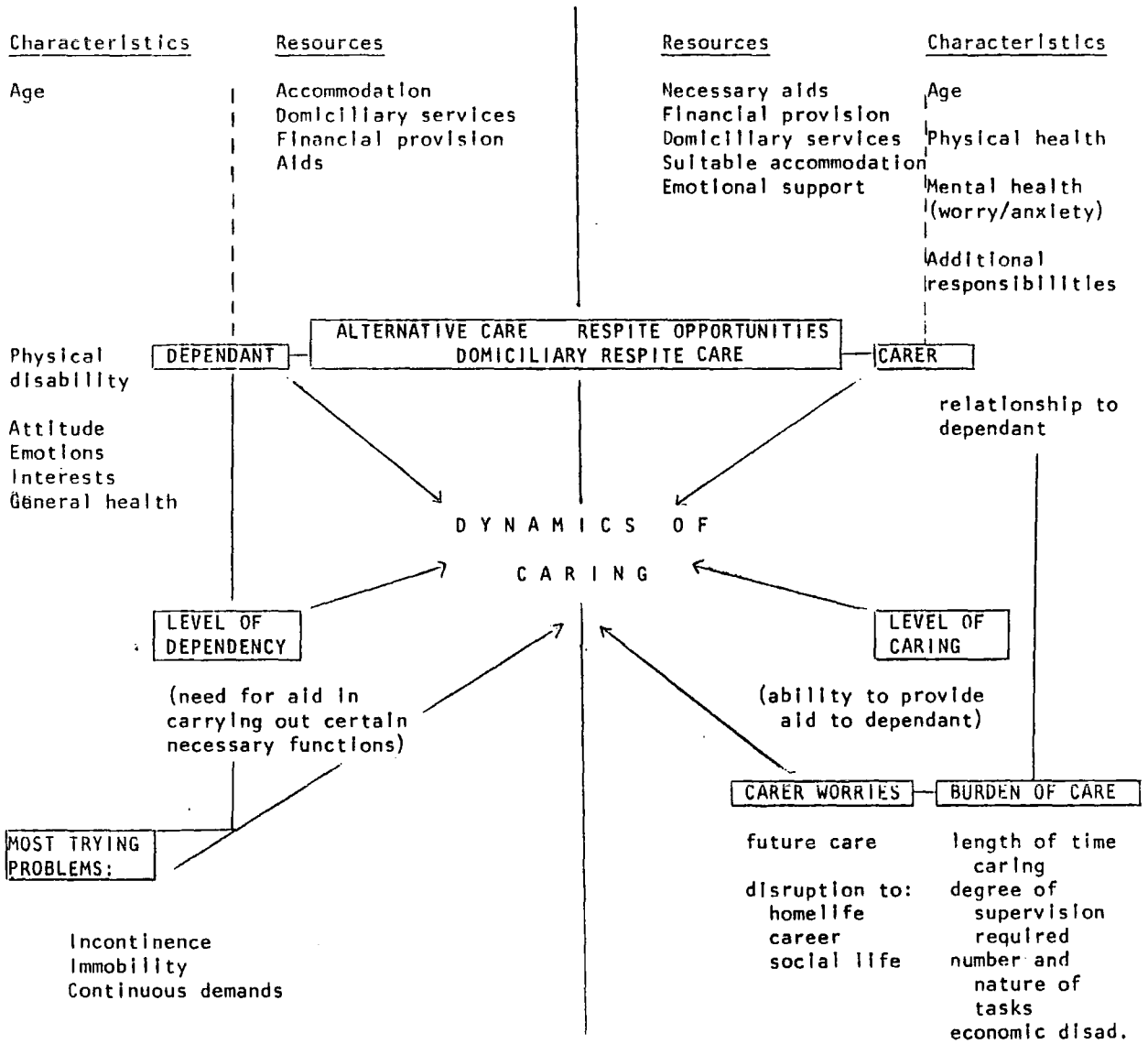
#### INTRODUCTION

Anyone may become a carer at any time. It may be a state that creeps up, catching people unaware, or it may arrive suddenly and dramatically, forcing a person into responsibility for another individual beyond the reciprocal roles of marriage and parenting. Caring can be exhausting, physically and mentally and result in social isolation and economic disadvantage.

The study shows that the degree to which carers are affected by their responsibilities is dependent upon a number of variables. Figure 7.1 shows this in diagrammatic form. By focusing on carers' experiences and the support they receive and may expect from others, this chapter considers the five prime caring related problems of health, tiredness, worries, being constantly 'on call' and social isolation, in the context of the informal support received from family and friends. It also draws attention to factors which have a bearing on the dynamics of caring: the personality and interests of the carer and the dependants and the additional responsibilities of carers, which are shown to have an impact on the family stability.

FIGURE 7.1

THE DYNAMICS OF CARING



The balance of factors in the caring dynamic can be used to assess family stability/instability.

The aim of the respite scheme was primarily to relieve the pressure on carers. It was necessary, therefore, when assessing a family for respite, to identify the signs of pressure, regardless of whether they were recognised by the carer.

The assessment procedure followed by the organiser used guideline questions to identify indicators and causes of worry. These were taken from the work of Cantrell et al (1977 and 1985), Lovelock (1981) and Crossroads literature (Bristow 1981, 1986, Bristow and Brenig-Jones 1983). Each of the studies cited devised assessment schedules for use in the field.

The rapid expansion of Crossroads schemes throughout the country in the past ten years (135 schemes - 1987) justifies the approach taken by the Crossroads co-ordinator during assessments of families. Lovelock's study of Care Attendant Schemes in Hampshire used the tools devised by Cantrell et al in their work with young physically handicapped people in Southampton.

The edited transcript of the interview with Mr and Mrs Stoner at the end of this chapter illustrates the health problems, tiredness and worry which affect carers. It shows the limits of informal support networks and the isolation and frustration which contribute, with the disability and characteristics of the dependant to an unstable caring situation.

## CARING RELATED PROBLEMS

### Physical Health of Carers

There are risks of acute physical injury associated with caring (Bonny 1984). Just as importantly, however, the unremitting pressure of care exacts a high toll on general health (Wilkin 1979, Wheatley 1980).

A woman in her late 30s caring for her mother of 80 years as well as a young family described how she felt:

"I've lost a lot of weight recently and had to go for some blood tests. I don't think for one moment there's anything wrong. Doctor says 'I think it's just the tension and strain'. I'm fit enough but it's the tension. I had this do in January when the floor kept coming up but he said it was just the tension."

Table 7.1 shows the carers' assessment of their physical health in relation to their age group and is drawn from the organiser's reports.

Seven of the elderly men caring for their wives described their health as good for their age. It is difficult to know if their assessments were realistic or whether a pride in their caring role led to an exaggeration of their physical fitness (Hunt 1978). The elderly women did not enjoy good health, all of them describing themselves as in moderate or poor health, and probably they were being more realistic than their male counterparts.

The health of the carer is essential to the continuance of a caring situation but often neglected (Hodder 1985). A dependant who is unable to manage any self care and is chair or bedbound will require lifting

TABLE 7.1

SELF-DEFINED STATE OF HEALTH OF ALL CARERS (n = 153)

Age	Good		Average		Poor		Totals
	No.		No.		No.		No.
	M	F	M	F	M	F	
20-29	-	5	-	1	-	-	6
30-39	1	9	-	3	-	1	14
40-49	4	15	-	8	1	2	30
50-59	2	11	5	9	1	8	36
60-69	2	5	2	6	4	4	23
70-79	5	-	9	10	2	14	40
80-89	1	-	-	-	1	-	2
90+	1	-	1	-	-	-	2
TOTALA	16	45	17	37	9	29	153
	61		54		38		

several times a day. The physical strain involved will be heavy and few carers are taught how to lift safely. They muddle through and develop their own techniques for moving their relative from chair to bed or commode and back again.

Gynaecological problems affected four women under 60 years of age and in each case the condition was the result of caring for a heavy relative. One woman who was severely anaemic was waiting to go into hospital when interviewed. Her health was so poor her husband had been admitted to a long stay hospital because she could not look after him.

"The strain of lifting caused the prolapse. The doctor said so and he said I mustn't try ever again. I did lift him an awful lot. Something had to give."

Years of such physical effort leaves many with back problems, reliant on osteopaths or pain killers, 'bad backs' are referred to by carers as 'their affliction' and early identification and training in lifting techniques could save thousands of carers' pain and distress. Elderly carers are particularly likely to suffer in this respect as the following interview extracts illustrate.

"I began to get cramp in my hands with all the lifting, and backache ... I got really worried."

"Because of the strain of looking after my husband my health is now poor ... Mr R. needed 24 hour a day attention. I suffered physical strain through lifting him after he had fallen out of bed."

Others feel the strain, physical and emotional, but try to hide it as long as possible and "I can't afford to be ill, everything would stop", was frequently heard.



### Tiredness and Sleep Loss

Tiredness was a major problem to most carers usually associated with loss of sleep (Bayley 1973). Loss of sleep becomes such an accepted part of caring that it was not consistently explored in the assessment visit although it was pursued in the interview in some depth. The inconsistent attention to sleep loss by the organiser to some extent reflects the reluctance of carers to dwell on themselves, but for many, sleeping lightly and rousing to cope with turning a dependant, taking a person to the toilet or adjusting bedding can be done for many years without a significant effect on health:

"(my) ... sleep is broken, I don't get a lot of very broken nights. Just normally once around 3 o'clock. I'm there for her when she does need to go (to the toilet)".

This elderly husband was troubled more by sleeplessness from disturbing dreams than the interruptions caused by his wife's physical needs:

"... it's silly dreams and that. I don't know why but they seem to go on for ever and ever and I wake up about three times in the night and it takes me quite a while to get off".

Another husband caring for his severely demented wife had difficulty sleeping and often felt very tired:

"I get me hours of sleep but I don't know if it does me much good. I can only get 3-4 hours if she's quiet. I'm often awake 2-3 hours. I read till I fall asleep: but I'll drop off for half an hour in the chair after me dinner."

For other carers tiredness is nearer to exhaustion. This lady had hoped her husband would settle in hospital weekend care:

"... I'd love to go to bed and not feel 'Oh God, I'll have to get up 3-4 times before the morning'. That's why if he'd settled for the weekend it would have been alright. Then I could have regained my strength with two good nights sleep."

Another carer suffered from leukaemia and was often exhausted:

"Sometimes he wakes two to three times in a night and at other times not at all. We get the partial attendance allowance 'cos sometimes he sleeps through; but some days its really tough going. Some days I just get on that bed about one thirty or quarter to two and I sleep. I can't do anything else ... me eyes won't let me. I think its partly me illness as well you know."

Sleep loss is part of the lowering experience of 24 hour a day care (Bonny 1984). The care needs which prevent a carer from risking leaving a person unattended for more than a few minutes during the day time and contribute to tiredness and raise tension:

"I was running, literally running, to do everything, 'cos he'd always attempt to do something when you're not there. You have to prepare meals so you're running in doing a little bit, running back." (Wife of a stroke victim aged 68 years).

"I couldn't leave her. You can't, she'd try to be all over. I can't even have a bath unless someone's here." (Daughter 62 years old with 83 year old mother).

"It's surprising how you manage when you've got to. I couldn't leave him, you don't know what would happen, he might fall. The only snag is - if I'm not well, and its been like it right through, I've got to get up 'cos he can't cook or anything, see."

Sleep loss, tiredness and the general 'grind' of caring can affect secondary carers. Mr Wright supported his wife's decision to bring her mother to stay with the family. The old lady became progressively more confused, with a serious effect on the whole family. Not only was Miranda's school work affected (p. 150) but:

"... Before they put her on this medication we never slept for weeks. She was screaming all night and getting in and out of bed dirtying the floor. When she talks like that thro' the night, no way can you sleep. I used to be down stairs at 4 o'clock ironing and washing. My husband drives an articulated lorry. He was going out in the morning having had next to no sleep. He really wasn't safe on the roads."

Carers were proud of their ability to manage and many made light of interrupted sleep. It is speculated that the carer who does not acknowledge the severity of broken sleep may not qualify for a full attendance allowance as the medical assessor is unlikely to probe the reality of responses to such questions. The following extract shows the result of accepting sleep loss as a normal aspect of caring:

"I only get a day allowance. Doctor came out and of course I was credible. I was crowing a bit and he says 'What she like at night?' and I says 'Oh she's great' so of course that knocked us out for night allowance!" (Mr Green).

Pride in coping with the pressures of caring reflected the devotion which characterised most of the relationships in this study. Carers gained satisfaction from doing the job well, and pleasure when that success was acknowledged (Oliver 1983).

### Carers' Expressed 'Worries and Anxieties'

Worry about the future preyed on carers. Lone carers with no one who could be readily called on feared what might happen if they were taken ill themselves. The wife of a confused elderly man who had suffered two heart attacks herself was pleased to have a warden on call:

"The Warden's good, she'll be over in no time if you need her but there's a limit to what she's allowed to do. I've got the telephone in the bedroom in case. My greatest worry is if anything happened to me at night. George wouldn't know what to do."

Parents caring for severely disabled children worried about the future care of their child and his/her adjustment to institutional care if no substitute was available in the community:

"She's never been in (hospital) even for a weekend for years. Its their attitude they don't treat her as a person. But its a worry. We can't expect Neil to have his sister with him all his life can we, and we won't live forever."

Some were more pragmatic like Mr and Mrs Stokes:

"We'll get her in for a weekend to get her acclimatised for the simple reason we're not going to be here for ever and it'll have to be some place like that she'll go if anything happened to us."

But Mrs Miles widowed with a 35 year old multi-handicapped daughter had a different solution:

"... I don't think about it. What's the point? I won't be here so something will have to be done for her 'cos she can't do a thing for herself."

Such verbal denial was not uncommon. Uncertainty about care options and knowledge that relatives would not take on new responsibilities forced many carers to cope "taking each day as it comes". The physical pressure on carers, their lack of choice and an inability, or fearing the inability to carry out the required practical care to ensure their relatives can stay at home produces scenarios like the following in which a married daughter caring for her non-resident mother suffering from senile dementia described her health crisis:

"I fell outside my mother's house after calling very early one morning on my way to work ... I broke my arm ... and I have received counselling and treatment by my GP for anxiety and tension due to the strain of looking after my parents, my father was an invalid for many years. I could not have managed without my husband's understanding and the care helpers gave us a little bit of time to be together. I still don't think I did enough for my mother but the doctor says those feelings are normal."

Mr. Frost gave up work because of the pressures on him as a carer:

"I'd often fall asleep at my desk with the tiredness. The doctor said the heart palpitations were stress and he put me on tablets for the anxiety. I can't afford to be ill though. Everything would stop; what would happen to Jane (his wife). I've still got to get up and decide what we'll have for dinner, and the washing ... Sometimes I'm so depressed I'd rather not go out when the girls come (the care helpers). Sometimes I just go to bed."

The female carers in the mediatic age group i.e. 20-69 years, although less inclined to describe their physical health as poor compared with

their peer group were just as likely as older female carers to admit to feelings of anxiety about the future and the effect on the rest of the family of the carer's responsibility for a disabled relative.

Table 7.2 shows that over half (81:153) of the carers visited by the organiser described worry they were experiencing.

Fifty six per cent of all female carers and 42 per cent of all males reported finding the responsibilities of caring were having a deleterious effect on their emotional and mental stability. The proportion is probably higher if account is taken of individuals' reluctance to admit to anxiety. Nevertheless self reported care related worry was a problem for 52 per cent of the carers. Eighteen per cent of those worried carers - five men and ten women - were taking anti-depressant medication.

The organiser assessed that all 45 carers in the 70 plus age group (29% of all carers) were experiencing anxiety and worry although again only a proportion of them (66%) expressed this specifically. Many talked in terms of their dependants future care emphasising the relative did not wish to enter an institution. This subtle pressure was particularly difficult for the elderly carers, 60 per cent of whom were caring alone. Dependants may, in turn, be affected by their carer's health, morale being lowered if cared for by a physically exhausted and emotionally fraught carer.

TABLE 7.2

CARERS BY AGE GROUP EXPRESSING CARE-RELATED WORRY AND ANXIETY (n = 153)

<u>Age</u>	<u>Male</u>	<u>Female</u>	<u>Total Carers</u>	
	<u>Carers</u>	<u>Carers</u>	No.	%
	No.	No.		
20-69	7	48	55	35
70+	11	15	26	16
	18	63	81	52

Constantly 'On Call'

All disabled people whose carers were supported by Durham Community Care were at risk of self injury or suffering severe discomfort because of their inability to perform some self care functions and many disabled persons needed constant physical care.

"She was never alone because she needed constant attention. I couldn't leave her so I never had a full nights' sleep."

"Well you can see for yourself. You can't sit in a chair and watch the telly, it's up and down, wiping her mouth or turning her. She's a so and so for getting herself twisted - you have to watch her all the time."

"I have to change him four or five times a day. The pads are no use. So with that and feeding him there's no rest."

The need for constant supervision, even if not continuous physical aid, was a drain for many carers who were afraid to leave their dependant for fear of what they might find on their return:

"I don't like to leave her (lady who had suffered a stroke) if she wanted to go to the toilet she couldn't get there and you never know who comes round the door these days."

"I don't want to leave him. He doesn't mind but I'd never leave him quite alone. I would worry too much."



One wife who did slip out to the shops learnt the hard way of the risks that can be attached to leaving a disabled person. Mr Edwards was suffering the advanced stages of multiple sclerosis:

"I was out at the shops one day, just for a few minutes, and he pulled the cord for the warden 'cos he wanted some pain killers and she came and gave them to him. The warden probably didn't think and left the tablets. When I came back he was slumped over his chest, like, I thought he was asleep at first then I realised something was wrong. I panicked like mad. I'd never leave him again."

Mrs Stokes' daughter suffered frequent severe fits:

"You don't know when she'll get one. The actual grunting and flinging and kicking about lasts about two minutes but it can take five to ten minutes to get back to normal ... I mean you literally can't do anything (more than hold her) she's that big and flinging her legs and arms every way which way. You have to try and stop her hurting herself. Its quite frightening if you haven't seen it ... I'm still not used to it, my heart goes thumping. I've just got to accept she'll take these fits."

Many carers respond to their dependants' unspoken fears and anxieties and like Mr Palmer did not leave them unattended:

"I stayed with her. We didn't talk about it but I knew she liked me to be there."

Such expectations are a burden in addition to the responsibilities of caring. If a person's safety is at risk few people would be able to ignore their need, but the result is a carer who feels trapped.

Mr Frost finds that unbearable at times, and reacts strongly:

"It's up and down the stairs all day. You've no sooner got down than she's on the bell. Will you straighten the covers? I want a drink. Why can't she say that when I'm up there? It's alright for her she can have a sleep in the afternoon. I've got to do the washing up and vacuuming. By night time I'm really shouting at her ... I throw pots and pans and I've broken a good few dishes - it's the tension she's so demanding ... I was at my wits end till this scheme started."

Table 7.3 below shows the frequency with which the carers who were interviewed had to provide help to their dependants. Only 7:23 (30%) could be left in the day time for 2-3 hours. But these were also the dependants whose carers feared for their safety if they were left alone.

TABLE 7.3

FREQUENCY OF HELP GIVEN TO DEPENDANTS

	No.	%
Constant supervision day and night	5	22
Physical help 2-3 times an hour and night time supervision	11	48
Physical help every 2-3 hours and once or twice a night	<u>7</u>	<u>30</u>
	23	100

Social Isolation

Caring can result in the disruption of social life (Bristow 1981, 1986, Wade et al 1983), and worst, the social isolation of the whole family (Tizard & Grad 1961, Bayley 1973, Oliver 1983).

As many as 26 percent of carers in the study said they had no contact with friends, neighbours or relatives on whom they could rely for any form of support. Although some did use intermittent care or day care provision, this still left 17 (11%) carers with no support from family or friends and no chance of a break.

All but one of these socially isolated families were known to a caring agency, half to the social services department, and seven were receiving care from a district nurse or community psychiatric nurse. Although the length of time they had been caring varied from just a few weeks to ten years, all the carers described themselves as being strained or exhausted by caring.

Isolation tends to increase with the length of caring (Blaxter 1976) and is an indicator of need for support from outside agencies (Thompson 1984) as caring becomes more intolerable over time (Levin et al 1983). However, carers, particularly the elderly carer looking after a spouse (Cresswell and Pasker 1972) have a low expectation of the help they might deserve or expect and quickly become isolated because they do not demand attention. The internalisation of a feeling of social inferiority which follows the loss of a job because of caring, financial restrictions and inability to get out of the house forces families into further isolation.

An elderly husband whose wife suffered senile dementia and had not been safe to leave alone for five years said he suffered badly from the emotional strain of isolation:

"I ... had tablets from the doctor to ease the strain ... I felt very lonely" because "I could rarely go out ... rarely able to get 'sitters' and friends stopped calling."

The enforced disengagement from 'normal' social activity leads to reduced expectations by others forcing carers into a cyclical problem which they face by developing a strategy for coping by maintaining they have no need for help (Goffman 1956).

For the majority of carers (116:153) the chance for normal social activities was possible only if their own social support network produced a substitute carer. Caring relationships however contain elements of reciprocity (Abrams 1977) and obligation (Finch 1983, 1986) which change over time. These changes reflect the pressures on relationships. Dependency and caring both restrict the opportunity to maintain an 'extended social network' and alter the quality of the 'care network' relationships (Hammer, quoted by Lentjes & Jonker 1985):

"In fact I don't think they come to visit, actually. If they want anything, or to tell me something, there's got to be a reason. But its always in and out and the car engine running."

Clearly the frequency of social contact is not the sole indicator of social isolation/integration as perceived by the carer but the quality of those relationships.

## INFORMAL SUPPORT NETWORKS

Informal support networks are interpreted in this study as the relatives, friends and neighbours who give support to the carer and dependant.

Lentjes and Jonker (1985) note definitions which identify three or four types of support; emotional support, esteem support and network support (Cobb 1976); emotional support, appraisal support, informational support and instrumental support (House 1981). The help offered to carers, defined by its functional content, includes all four types of support but primarily focuses on the emotional support provided by a carer's social network and the practical help which meets a specified need. Neither may meet the carer's need for respite.

The use of terms 'friend' and 'neighbour' raises problems of definition (Robinson & Abrams 1977, Allan 1979). The safest definition, therefore, was that given by the families themselves and gleaned from the assessment visits of the organiser, or the interviewed sample.

### Relatives of Care Givers

Relatives, usually nuclear family members, were the providers of most practical and emotional help to carers but the form of help was invariably limited and usually excluded personal care of the disabled person. Altogether only about one third of carers (48:153) described having contact with other members of their family and two thirds of these relatives(15:48) helped with the personal care of the disabled person. In three families the disabled relative moved between households spending

part of each year with different relatives (in each the dependant was a disabled parent). These might be described as near perfect examples of shared care and a similar level of co-operation between children of a disabled parent occurred in two families where the carers were non-resident. Mostly relatives helped by babysitting for disabled children, giving the parents a break, helping put a person to bed or taking over daytime care when the main carer was out or at work.

"Me mam was a good help. She'd even take Dorothy to her house for a weekend but I lost her 18 months ago. You don't realise how much your mums do for you. His mother will come but she'll only sit with Dorothy. She couldn't do anything for her." (Mrs Stokes)

"She (aunt) takes her (mother) to the toilet and generally looks after her but she doesn't put her to bed. Me own sister next door comes in two half days a week but her husband's not well so she doesn't do a great deal." (Mrs Jones)

An unexpected crisis can bring families together and a high level of practical support may be maintained for a long time. The following was, however, a story of remarkable sustained co-operation:

"Unfortunately everything went wrong and he had a heart attack in the operating theatre and when he came home he wasn't even as fit as what he was when he went into hospital. He was never left alone at all and with this illness he was cared for almost a full year from coming out of hospital to when he died ... we managed as a family to look after my father, one of my aunts was at our house every day ... while my mother stayed upstairs with my father. We didn't ask for any other help from the authorities other than to ask them to put in a stair lift so that my father could come down stairs. We were given a wheelchair but until Durham Community Care came we weren't able to use it."

Secondary carers prepared to support the main carer in all caring tasks could be an important factor in preventing breakdown in a caring

situation. Unfortunately they were not always available and the benefit they could give varied accordingly.

"My niece will help wash or dress if she's around but she works in Ferryhill. She's more emotional support."

Even when distance was not a problem carers reported limited personal care help with their dependant.

"No one will take her off my hands to give me a break. I know I took her on voluntarily but I'd still like a break." (Carer of mentally handicapped adult).

For parents of disabled children the sense of responsibility for that child had often resulted in them excluding other children from caring. Knipscheer (1985) describes such carers as 'prisoners of love', focusing their lives on their dependant and guarding their caring tasks from other possible helpers. He notes that such descriptions apply especially when the central care taker is a spouse, but in the following example an elderly mother carried out most of the care of her son.

"My daughter finds it distressing. She can't cope with her brother the way he is so we don't ask her. She comes and sees us everyday and does my heavy shopping. The granddaughter comes on her way from school. They're good to us but Terry's our responsibility."

Sometimes the life cycle of families removes another pair of hands.

"Peter was always here 'till he married three years ago. He was another set of muscles and used to help his father with David - I haven't been able to lift David for a long time, he's a heavy boy. I don't think we realised how much we'd miss Peter's help."

Many families who had social contacts with relatives (and friends) (74%) had help in the form of domestic work or shopping. It is possible that those relatives may have been more ready than the carer supposed to step in if a break down seemed imminent, and irregular visitors may have increased and modified their support.

On the surface, household composition might appear to be a factor in receipt of practical support and the presence of other adults could result in shared care. This did not appear to be the case, the responsibility for intimate care devolving on the spouse or daughter (Nissel and Bonnerjea 1983, Wright 1986).

"Well he's a good help. He'll sit with her but I suppose you can't expect him to do that (change incontinence pads) for his mother." (Mr Frost).

Three generation households or carers sharing care with another adult were no more able to find a substitute carer than lone carers. Grandparents may sit for a disabled child but babysitters are less inclined to offer their services if a frail grandmother has to be looked after as well. Daughters caring for parents seem to have particular difficulty arranging evenings out with their spouses:

"They don't mind baby-sitting, but when they realise one of the 'babies' is nearly 90 years old nobody wants to know." (Mrs Wright).

### Friends and Neighbours

Carers feel unsure and embarrassed about asking a friend or neighbour to take on personal caring responsibilities. Even offers to



sit with a dependant have to be taken up sparingly in some carers' views for fear of abusing a kindness or running out of credit (Blaxter 1977, Abrams 1981).

"Shopping, business appointments ... did become a considerable problem once my mother couldn't be left at all, since one can't really make unlimited demands on friends for very extended periods."

"She said, 'just call me' but you don't like to bother people, especially at night." (Mr Smith).

"The next door along are very kind. I've only got to ask her but I don't go and ask. It's nice to know though that I could but she's not a very fit person. She's got asthma and hardly goes out herself." (Mrs Winter).

Some will resort to asking for help in an emergency:

"If we get into difficulties the neighbour will come in. He's a pitman but he's often on late shift. When he was on strike of course he was always there. Now I'd worry about disturbing his sleep." (Terry's mother).

Many carers had spent a lifetime in close contact with neighbours and such social interaction with people living near by could be a great advantage to them. Mrs Farmer had a good relationship with her neighbour which she classed as a friendship. Despite moving house this relationship had been maintained but could no longer be of immediate practical help:

"I should just knock on the wall and they'd be in to help if I needed anything if he fell. We didn't run in and out of each other's houses but it was support. Marvellous support. I miss them, but we keep in touch."

Mr Brown, on the other hand had lived in his house for 30 years caring devotedly for his wife who suffered from senile dementia and was incapable of any self care or speech:

"They're neighbours on the other side, you don't know them. They're friendly enough but the young people they're always chopping and changing. You don't know them well enough to get help. The lady above my son, she says 'if you need anything let me know' but luckily I haven't need it.

To be honest we never did bother much about neighbours. We had friends we used to knock about with but Molly didn't like gossiping so she didn't go out to neighbours houses to talk neither did she invite them back to talk. We just, why we were so close we were just content with our own lives."

Only five (5:153) carers had friends who gave personal care to their disabled relative but nine (9:153) were relieved of some of their domestic responsibilities by neighbours and friends.

Table 7.4 shows the incidence of practical support (personal and domestic) and emotional support given by relatives, neighbours and friends to the carers interviewed. Responses were, of course, subjective, liable to inaccurate recall or deliberate falsification but do represent the carers' feeling about the support they received. The figures refer to the number of contacts, in terms of the carers' reported type, source and frequency of help. Relatives are the most usual source of practical and emotional support. Telephone calls being a frequently referred to means of keeping in touch with relatives and friends living away from Durham. If practical and personal support is given it is more likely to be on a frequent basis (at least weekly), rather than provided from time to time.

TABLE 7.4

SOURCES AND FREQUENCY OF HELP GIVEN INFORMALLY TO INTERVIEWED CARERS

Nature of Help	Frequency of Help									Total Contacts
	At least once a week from			At least once a month from			Occasional from			
	rel.	fr.	nbr.*	rel.	fr.	nbr.	rel.	fr.	nbr	
<u>Practical</u>										
domestic	8	1	1	-	-	-	2	-	1	13
personal care-depandant	5	-	3	-	-	-	-	-	-	8
<u>Emotional</u>										
visits	14	-	9	2	-	-	-	2	-	27
telephone calls	4	-	-	2	9	-	3	-	-	18

\*rel = relative  
fr = friend  
nbr = neighbour

Sometimes a complete stranger is the best or only answer when practical help is required, particularly with lifting which can be a major problem for many carers:

"Three times on the Monday she'd fallen down, slipped from the chair, sliding down to the floor. She's strong you know. At the third time I just had to knock on the window and get someone in off the street to help. I just couldn't lift her any more. She's a dead weight, just limp 'cos she doesn't know what to do to help."

"What I used to do when he was downstairs. I'd go outside and ask the first gentleman who was coming along 'Excuse me have you got the time to help my husband up the stairs?' Of course next door were good, he'd come in and help but I wouldn't disturb them at night."

Twenty two carers (22:153) had friends and neighbours who called in, sometimes daily and shared a few minutes with carer and dependant.

"She pops in and is on the 'phone most days. She's more like a sister really. I rely on her a lot." (Mrs Farmer)

"I've known them a long time but they've got their hands full during the day so they can't come and see me. So I generally go to see them on a night when me husband's in to look after Dorothy. They're very good. They'll ask how she's been and me ... anything that's bothering me. I can talk it out. They're quite good like that really. 'Cos they've got families and they've got problems, maybe a different set of problems, but they've got family the same." (Mrs Stokes)

Mrs Eden looking after her husband who had suffered a stroke and major stomach surgery felt desperately in need of help:

"There's just no one, I go upstairs and cry for hours but you can't talk to people about how you feel, certainly not Joanne (her adult daughter), she's not settled herself and my worries would tip the balance. I'd end up visiting her in hospital."

It might seem that family members would be the obvious source of emotional support but this did not always seem to be forthcoming. Parents in particular did not seek support from other family and the following extract illustrates the point that carers often draw limits around their capacity to care (Knipscheer 1985).

"I wouldn't moan and complain to each of my children. I mean we don't really moan and complain to each other. If we started doing that we'd be absolutely finished. We just go on from day to day. We've learnt in the past year that if you are feeling stressed you do something about it. You go to a professional." (Mother of son with spina bifida).

Miss Hyde also relied on professionals. She had psychiatric problems of long standing but caring for her mother had given her a period of stability.

"The nurse (C.P.N.) gives me an injection once a fortnight. She has time to talk, that makes a difference when you've no friends."

Apart from Mrs Farmer who clearly was receiving what she saw as a sibling's support from her friend, there was little evidence of family, friends and neighbours substituting roles. Townsend (1957) had noticed that:

'people without relatives intensified other associations. They exchanged visits more often with neighbours and friends ...'.

Carers may possibly wish for such associations but the reality was, as Wright (1986) found, that neighbours and relatives have different functions. The more dependent the relative and the more intimate the care needs the less likely the carer was to have practical help;

neighbour and kin roles were more clearly defined and kin less likely to substitute for the carer.

Carers did not always seek help particularly if they thought it might be reluctantly given even when they felt help ought to be forthcoming:

"He's down 2-3 times a week but never stops. We don't see her. She never calls, never looks in. But as family I don't think you should have to ring up, they should just come and see if you need anything. They go round helping other people ... But I cope and I think sometimes you can be that much too efficient ... They think you can do it so don't think you want any help. I can hide a terrific lot. It's my own fault I suppose but I'm like that. I'm very independent."

Mayer and Timms (1970) assume that most people resort to informal support networks before seeking help from professionals but they describe two types of 'client' who may resist using networks, 'non-communicators' and 'unsatisfied communicators'. The lady quoted above fell into the non-communicator category. The normative restraints of a life time and stiff 'upper lip' combined with a fear of 'withdrawal' by her family prevented her asking for help.

#### OTHER FACTORS AFFECTING THE DYNAMICS OF CARING

##### The Personality and Interests of Carers and Dependants

The carer who seems to take on the 'tending' (Parker 1981) tasks with relish, is even tempered and continually bright and cheery, will probably be a more comfortable person for the dependant to live with than someone who is resentful and exhausted (Oliver 1983).

Such carers will have the admiration of friends and professional care givers and they may or may not be 'rewarded' with 'extra' support from such people (Blaxter 1976). The 'off the record' comments of referring agents, district nurses, social workers or volunteers who come across irritable and exhausted carers show the tendency to criticise carers who give way to 'difficult' behaviour. Stockwell (1972) argues that care becomes difficult when patients fail to respond in improvement or gratitude. This research is suggesting secondary carers (extended family and friends) and professionals lessen their interest when a carer does not appear to respond to help in a grateful way.

"After a while they stopped coming. When they know what's involved you'd think they'd help more but really, I mean, you see less of them." (Elderly man caring for his wife and referring to his children who live away.)

"They seem to have a down on me. I complained about the ward. It was dreadful he was in such a state. The doctor does not have any sympathy. He wouldn't support the hyperbaric chamber idea. No one seems to listen to my ideas."

Cantrell et al (1985) suggest that the ability of carer and dependant to maintain a hobby or interest is important in maintaining 'well being' in the caring situation (DHSS 1975). An interest beyond the daily 'tending', will help carer and dependant to maintain balance in their relationship. In the present study, however, the dependants were generally more disabled than in Cantrell's investigation and few were able to entertain themselves.

"She's not the same woman, she used to be full of energy, running the table tennis club for the youngsters and taking dressmaking classes, she taught embroidery too. Now look at her - even reading bores her."

Carers also found it very difficult to maintain hobbies and interests particularly any which involve going out of the house:

"Your life stops, it changes completely. All the social side just fades away. We used to go to the R.A.F.A. club but for the last few years we just haven't been. I can't get out."

Mrs Dale had been an active church member and sat on several committees:

"They ask me to go along, but much as I'd love to go and they say they'd send someone to be with him, I wouldn't relax so there's no point. It would be more of a worry then. It's lonely though. He can't talk to you and the television's no use. The granddaughter tries to play dominoes with him: he tries but really..."

Miss Jones looking after her mother had not expected such a restricted retirement:

"When you retire you think you'll be able to do things you couldn't when you were working. I can manage a game of bowls once a week but that's all. I knit but you feel trapped. I think I miss the company these dark nights, sitting and having no one to talk to."

Once confined to the house most women carers had little energy for anything beyond television and knitting. Male carers seem more able to maintain interests outside the home, particularly gardening and visiting a club or pub and when relieved by Durham Community Care helpers were more likely to use their time pursuing hobbies than were female carers who used the break to catch up on outstanding domestic work. Women were less likely than men to have help in this area in common with other research findings (Charlesworth, Wilkin and Durie 1982, Wright 1986).



"I've an allotment and when the girls (care helpers) come I've got two hours down there and I really feel the benefit of it. To me I can relax in a garden. That's my main outdoor activity and the weekends she's in hospital I get a lot done. And I go to the club. I'm very keen on dancing. Molly and I used to go every week and I still love it. I've found a couple of partners like me daughter-in-law and her friend and I really enjoy it."

A sense of humour is a great asset to a carer. Terry's mother, recounting the problems she's had lifting her son said she had horrified the district nurse:

"She said, 'How have you been managing?' and I said 'Oh we manage! My knee comes in handy when we're trying to sit him up in his chair. This knee comes out and we give a heave and hope' ..."

Others gain strength from their religious convictions:

"I've a strong faith in God dear, and I think that's what keep me going. If I didn't have that, I don't think I could cope with what I have to do."

"I feel God gave me strength and energy to do this work. He has been guiding me like he did with Lepra." (this lady was a Lepra fund raiser for 10 years whilst caring for her husband and before taking responsibility for her sister).

Both of these ladies talked of the patience and calmness they felt their faith had given them.

#### Additional Responsibilities of Carers

More than half the carers (87:153) had responsibilities over and above the care of their dependant. Women running two households, looking after young children (one in five of the daughters) and going out to work. It is not surprising that few of the carers, particularly the

women had time for socialising. Table 7.5 shows carers with additional responsibilities.

Although going out to work undoubtedly placed additional physical pressure on carers, the opportunity to maintain some independence and feel normal was essential to the 'sanity' of some women:

"Well I never thought I would end up charring. But you know I really look forward to that two hours. I get out of this house and I can have a bit chat with the girls and forget about this, I begin to feel normal. I wouldn't give it up." (Mrs Wright)

"The money's vital but to me its being able to have a gossip and be with your mates that's most important." (Mrs Storey)

Another carer, a mother, had a full-time job as a teacher and prided herself in missing only two days work when her son was ill six months previously:

"I've worked since he was born. Part-time at first then full-time since 1973. So really we just work our lives around the whole thing. We're quite happy. We're lucky we've got tons to do and we certainly don't make a chore of him."

#### ASSESSING FAMILY STABILITY/INSTABILITY

Relationships are not static but respond to external and internal pressures experienced by the parties. For carer and dependant the coping mechanisms which are devised help to determine how well the adjustments can be made. At any specific point incompleteness of adjustment by any party can strain the relationship. For younger carers the change of role if a husband or wife is suddenly forced into

TABLE 7.5

CARERS PRIMARILY CARING FOR A DEPENDANT AND CARERS WITH WORK AND FAMILY RESPONSIBILITIES IN ADDITION TO CARING FOR A DEPENDANT

Relationship to disabled persons.	Primarily carers (n = 66)	Carers with additional responsibilities (n = 87)
Spouse	44	17
Sibling	9	2
Parent	4	15
Daughter	7	38
Son	2	9
Niece		2
Grand-daughter		1
Neighbour		3
TOTALS	66	87

a dependent role is particularly difficult to accept. The birth of a handicapped child can result in a range of emotional responses from anger and rejection, to feelings of deep loss and mourning (Bayley 1973, Glendinning 1983) for which coping strategies have to be developed (Martin and Mulick 1983, Friedrich et al 1985). Carers of all ages caring for dependants of all ages are given little chance to mourn the loss of the person who has changed and is changing before them.

The dynamics of caring must be recognised and this has implications for all professionals connected with domiciliary and residential care whose past concentration on the symptoms of the dependant have hindered the adjustment of carer and cared for (Greengross 1982, Stephenson 1982).

Cantrell et al (1985) developed a Household Index to indicate the stability or otherwise of families with physically handicapped members. The tool was used as a means of assessing 'at risk' families in Southampton and validated through a longitudinal study of those families. Lovelock (1981) modified Cantrell's index for his study of Care Attendant Schemes in Hampshire. With the addition of four factors, concerning the carer's responsibility for others and relationships with dependant, other family members and professional carers a similar index was evolved for this study. The 'intrinsic' factors refer to the dependant, with the lowest possible score for the least dependent disabled person at 27 and most dependent at 88. On the axis representing 'extrinsic' or carer 'stress' factors the least stressed scored was 15 and most stressed had a potential score of 76. The scores are derived from the interview questionnaires used in the family survey (see Appendices 3 and 4).

Figure 7.2 is the completed Household Index with the frame divided into quartiles. The index shows each of the families in the interview samples over the two years of the study. For those families who appeared in each sample and were interviewed twice the change in score (if any) is indicated with an arrow.

This index could be used as in Cantrell's study to indicate 'unstable' families which he suggests lie in the YC, YD, ZD and ZC boxes. Cantrell devised the tool for preventive intervention. Lovelock (1981) used the same indices as Cantrell but reported more severely 'unstable' families being cared for in the community and a similar level of instability was found among families in the Durham study using the modified index.

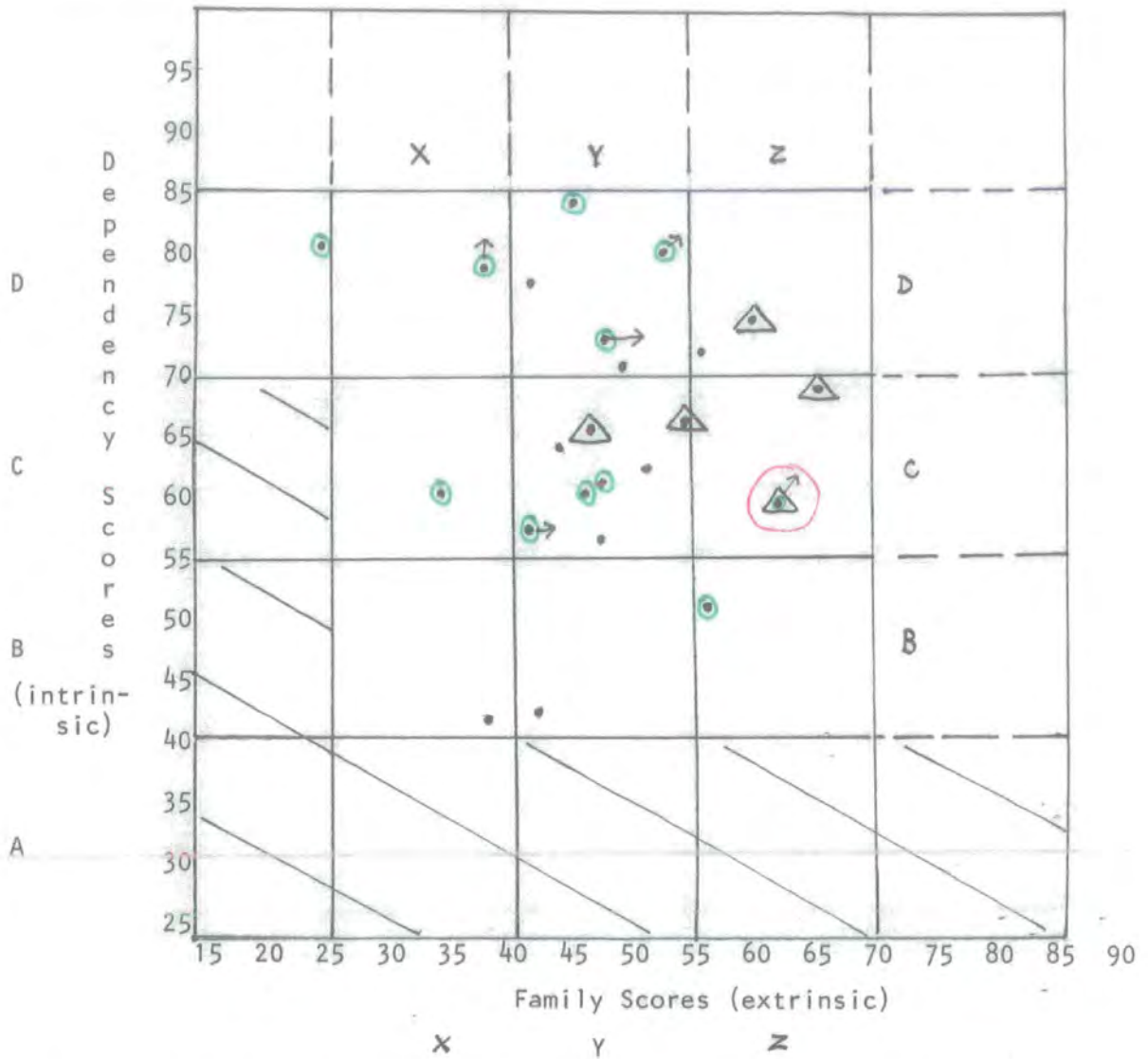
The index could be a helpful tool if used in a domiciliary respite care scheme to observe and monitor changes in families receiving long-term care. The triangled families ( $\triangle$ ) on Fig. 7.2 refer to those where the dependant had a deteriorating condition and the prognosis was, (from observer observation) likely to cause additional pressures on the family.

The following transcript of the interview with Mr & Mrs Stoner illustrates the pressures on a carer which lead to an unstable situation. Mr & Mrs Stoner are represented on the index by a triangle encircled in red.

Fig. 7.2

FAMILY CARE INDEX

Families Interviewed 1985 and 1986



△ dependant with rapidly deteriorating medical condition

Key: 1985 families ●  
 1986 families ●  
 Mr & Mrs Stoner △  
 Families interviewed twice ● →

Dependency 'scores' of disabled people

A >39  
 B 40-54  
 C 55-84  
 D 85

Family 'scores' - carers' 'stress' factors

X > 39    Y 40-54    Z 50-70

EXTRACT OF INTERVIEW TRANSCRIPTJack and Lizzie Stoner

Jack is 89 years old. Lizzie 87 years old.

Lizzie suffers from senile dementia and she can do nothing for herself.

The couple live in a first floor council house.

"When it started in the first instance I didn't think much of it. She used to run off with the neighbours' brush and pail and say it was hers, and I had the pleasure of taking it back. But Mrs. Bell, she used to understand. She's just gone on and on and on 'till she's got worse. I've had to clean her down at 7 a.m. this morning and I had to do it prior to you'se coming and I've got to take her clothes off and sponge her down. Now Mr. Oxley (CPN) he takes the bed sheets so its not so bad but as the weather gets better I'll have to start and wash the bedding and that's how I get thro'. But I've worked among dirty clothes all me life - I was a van man for the Provincial Laundries for 53 years so there's not much I don't know about dirty clothes. But it gets a bit monotonous now, every day with her ... very trying.

She goes into Westcliff for a couple of weeks and if its going to do her any good you don't mind but she's comin' back no better ... every bit as bad, in fact she's gettin' worse. I'd hate to put her away. That would be the last thing, I'd hate to do it, - but I'm afraid that's what it will all end up with.

She's doped to death at night. Dr. Thomas, she gave her a good bottle. She has that at 9 p.m. and it lasts 'till about 6 o'clock in a morning - but last Wednesday I had to get up at 3.30 a.m. She's wet thro' and I had to change her and she's like a drunken man and believe me she takes some holding on to.

The days already organised with all the work. I do all the cleaning, all the washing. I'm not the world's best chef but of course under the circumstances what she can eat and what she can't ... and when Theresa (the care helper) comes I do me shopping, on a Tuesday and a Friday and if I want anything out of the way, a vest or something she'll say 'I'll get it', and that's a great help.

I mean you can't expect a man to go into a drapers and ask for that sort of thing. I mean to say, she's been very kind that way.

When she's in Westcliffe I used to be taken by me friend in Framwellgate Moor to see her. He takes me up to his house for me dinner too, when she's in there.

Dr. Downing comes in once a month to give her her prescription. He says 'Are you managing?' I say 'Only just'. It gets very trying, very frustrating, that's the only trouble, you just get to breaking point. If things didn't go wrong so often you would put up with it. It's a trying time.

I tell you this much - I miss her dinners, she used to make some smashing dinners, she were a good cook. What I see of these tins (meals on wheels) is it sufficient for a man? There's some things she won't entertain and you don't know how she'll be. I mean to say, yesterday I boiled her an egg for her tea, lightly and she left half of it. I mean, what can you do? What stuff do you get in? She'd like leave the meals (on wheels).

She's getting a bit unruly like, with her table manners. I have to put paper on the floor to catch the mess, that's the capers you have to get up to.

I have to wash her and a nurse comes on a Monday to give her a chair wash.

If anything happened to me they'd have to put her away. There's nothing else for it, they'd have to find her a place.

We don't have any conversation and she's no interest in the television. She trails me to the door a thousand times a day and there's nobody there. "there's somebody at the door Jack, there's somebody at the door".

You're tired. Believe me. Come 9 o'clock I'm glad to get to bed.

I have a sister in Thirsk. They run a big car but I don't see much of them.

They were here about 3 weeks ago, but they don't do anything, they maybe stop about 3 hours and away they go again. That's one thing I like about Theresa, she's a good help. We've got relatives in Coventry but they're out of work and its only a card at Christmas. Really I'm high and dry, apart from these at Framwellgate Moor and Theresa.

I worked till I was 70 years and then I got a part-time job for two and a half years. But in the end they were taking it all off me in the tax, but to me retirement is all wrong. I hate it. I worked for the laundry for 53 years and when I retired I got the usual gold watch! And now this.

We lost a little boy at three and a half years and she was really bad. She got a lot of help from working in the shop in Claypath but I don't think she ever really got over losing him, and sometimes I think that's where a lot of the trouble started.

She fights with me sometimes. She gets a paddy on her especially when its bed time. She'll go to bed with piles of clothes on, she's always cold. She hardly gets out, thats one of the troubles. I sometimes think her eyes are failing and she's lost her bottom teeth. We can hardly have a conversation, the way I am (very deaf) and the way she is. Its hard work!



Mrs. Bell says two or three times, if I had any bother I was to go for her, but you know you don't like to bother people especially at night. I just get up and make do and mend.

You get too old to dream, honey. That's the trouble. I had an allotment, me dad and I had one years ago. I had a greenhouse and all me poultry and I had bought a plough before I retired with a view to having something to do. People was always coming. 'Can you let us have a cabbage, a cauliflower? Here's a bob or two'. It was all a bit fiddle but gave me something to do. But they (land owners) pushed me off. I had to get off. They gave me two weeks notice. I had to burn the lot. Never again. It was terrible and now I wouldn't have the time.

But I'm pretty fit still. I have tablets off the doctor for me blood pressure and apart from that I don't do so bad for a fellow of my age.

Bob (CPN) suggested all sorts. But they're no good to me. I don't want a home help, they only clean and these places don't justify it. Give her her due (Theresa) she'll put her hands to and do anything. She'll wash the clothes, anything, that's what I've always admired about her. If she sees a job needs doing, she'll do it. No matter how filthy it is. You don't need to ask her.

You know, I'm afraid I do get angry with her at times. It's just a case of frayed tempers. You can't do anything about it. You've got to let off steam or you'll explode. You shout and afterwards you think, maybe I shouldn't have said that, but mind you, you've no idea what its like every day of your life."

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Mrs Stoner fell in hospital while receiving intermittent care four months after the interview. She died two weeks later without returning home.

## CHAPTER 8

### FINDINGS: FORMAL SUPPORT FOR FAMILIES

#### INTRODUCTION

This chapter examines the formal support available to carers in the study and considers the opportunities for respite care offered to the families. In giving attention to the impact of intermittent or short term care, day care and domiciliary services on the carers and dependants in Durham it explores the provisions discussed in Chapter 2 and the role of the scheme in filling gaps in statutory provision at a local level. The chapter concludes with some observations on the financial situation of the families and their housing.

The chance to have a break from caring aids coping with a dependent person (Wilkin 1979, Oliver 1981, Gray 1983, Stephenson 1982). As explored earlier, respite care may be provided through an informal support network of friends, relatives and neighbours or through formal care systems. Formal care systems were identified by the Wolfenden Committee (1978) as governmentally mandated or sponsored services. As such formal care refers to 'statutory' services. It also includes private practice, if controlled by either regulation or reimbursement, as well as services provided by voluntary organisations in receipt of financial support, in some form, from Government. 'Statutory' services is used in this study, as in the Wolfenden report, in the wider sense

to mean services provided by central or local government not in the narrower sense of something established by Act of Parliament.

Froland notes the difference between the basis of formal and informal helping. Professional or formal helping is generally based on:

"... standards acquired through training agencies; knowledge and expertise are valued in establishing the credibility of help provided. Informal helping is based on informal personal relationships, shared experiences and altruism and their credibility is determined by norms of exchange within the network."

(Froland 1981)

The informal patch based systems of service delivery relying on network of local people to provide tending and general support, either giving considerable latitude of assessment and action to the front line worker (Hadley 1981), or using a skilled social work assessment and a cost effectiveness approach (Davies 1981), are examples of developments in community care which incorporate the needs of carers of elderly people. However such care patterns are not widely followed, and are not usually directed to carers of non-elderly dependants.

There are examples of schemes which are being developed by local authorities to provide domiciliary respite to carers (e.g. Hampshire Social Services Department, North Tyneside Social Services see Chapter 2) but the predominant social services attention is geared to the dependant and his support in the community (Hodder 1985).

The primary means of respite care provided by the state to carers continues to come, therefore, through removing the disabled person from

the home and caring for him/her in a hospital or local authority or voluntary home.

Some local authorities, for example Sheffield, are experimenting with 'foster home' intermittent care placements for elderly people, on the lines of services for children, but rarely will host families take the most severely disabled people (Leat 1982).

Before 1984 no domiciliary respite care was available to families in Durham either via voluntary or statutory services. The statutory support offered to families remains dependant oriented and is provided by the primary health care team and social services department.

#### SHORT-TERM RESPITE CARE IN DURHAM

Twenty nine (29:159) disabled people - all adults - had periods of care away from home in institutions. In this study as in that carried out by Wade et al (1983) on the care provision for the elderly, short-term care was limited in availability. That provided in Durham, however, received lower satisfaction reports from carers.

Two children went to families in the STAR (Short Term and Respite) respite scheme. The STAR scheme in County Durham has been supported by the children's charity Dr Barnado's and joint funded by the social services department and health authority. Children with a mental handicap are placed with substitute families for up to two weeks at a time.

About one third of the intermittent respite offered to all carers was for holiday relief (10:29). It was therefore providing families with just two weeks break a year. One man with motor neurone disease was offered a hospital holiday bed. However, he was so disabled the staff found they could not provide the constant care he needed and so his wife stayed with him in hospital, completely defeating the object of the exercise.

Those people who had regular intermittent care were severely handicapped and again hospital beds were offered (19:29). Eleven of these very dependent people were suffering from severe senile dementia, four had suffered strokes, and four had multiple sclerosis.

The carers' view of intermittent care varied from appreciation to hostility. Many reported that they accepted the breaks reluctantly. They needed time without the responsibility of caring, but worry about their relative's distress, problems of visiting and dissatisfaction with the quality of care provided as noted in Chapter 2 lessened the benefit intended to the carer (Owens 1987).

Mr Storey had multiple sclerosis, he was chairbound and had severe bed sores dressed daily by the district nurse. He was cared for by his wife who also had responsibility for two rebellious teenage children and a hyperactive three year old daughter. Mrs Storey had a cleaning job five nights a week. She suffered from asthma and admitted finding

difficulty coping. She agreed, reluctantly, to her husband taking a respite bed in hospital for two weeks:

"He hated it; so did I. He was left in his own mess, wet all day. I'll fight to keep him at home and I'll fight to keep him alive... but I wasn't coping - I was getting buried in it... But he won't go back; I'll make sure of that, some how".

Miss Jones felt more ambivalent:

"I sometimes think it's as much hassle when they're in hospital as when they're at home. She (her mother) would often be crying when I got there and wanting to be out."

Dependants sometimes acknowledge their ambivalence. Mrs Frost remarked about the hospital ward for the young chronic sick:

"I think I would be better away from home sometimes. Then when I'm in I want to be out."

The distress of a relative usually produced a feeling of guilt (Jones 1986). Mrs. Farmer who was waiting for a hysterectomy knew her husband was distressed in hospital:

"I get this terrible guilty feeling. You feel so bad, as if you've let everybody down. You ask why does it happen to me?"

Mrs Gibbs was very disturbed by the prospect of two weeks intermittent care for her sister who suffered from Alzheimer's disease:

"I felt all upset. I don't know if I feel guilty. I've got a fortnight for her. I need it but I know she's my sister, I should look after her; but I'm tired and I can't manage another five years or so without a break. Its because there's no communication, no gratitude, its just take, take and animosity with her. I know its the

complaint but it still hurts ... I've aged ten years since I've had her. That's why the intermittent help is so good. She's getting used to somebody else. I'd rather have her at home. I'm not trying to push her on. I know they're good, but sometimes you get someone who can't resist the temptation to victimise people who can't stand up for themselves. It does happen. No way will Jenny go in full-time if I can help it ... I feel very tired but I think its emotional, its the worry (about intermittent care)."

Mrs Gibb's anxiety was partly because her sister was to be admitted to a mental illness hospital as her condition had deteriorated to the point where she was considered unsuitable for intermittent care in a local authority residential home.

The location of beds was a recurring problem for relatives who invariably found hospital care an unacceptable option, focussing on their dependants' inability to settle (like Mrs Winter), or the quality of care. Mrs Brown was admitted to hospital as a weekend patient once every two months:

"This time they didn't say anything when I came into the ward to collect her. And you see the size of the blister, its the size of a large potato and she'd got her slippers put on. Goodness knows how. There was no explanation. Its a mystery and they're keeping it to themselves".

Mr Brown was describing the hospital care used also by Mrs Wright's mother:

"St. Mary's used to have her intermittent for two weeks in and four weeks out which was great. Then they turned round and told me they couldn't cope with her. That made me laugh really... Now she gets into the Lawns for a weekend every 3-4 weeks. They used to let her wander about. She used to come out black and blue with bruises and her nose split. I played war, but they haven't got the facilities. They haven't any geriatric chairs for a start! They sit in an office and observe them through the glass. By the time she's stood up and they've seen, she's on the floor."

Mrs Wright, with many carers, felt she must accept such unsatisfactory arrangements for fear of appearing to cope and then losing all respite (Jones 1986). This 'Catch 22' situation was most acute for the carers of most heavily dependent relatives for whom day centres, luncheon clubs and visits to friends were impossible because of mobility or behavioural problems. None of the carers interviewed (23:159) was looking after a relative who was being admitted to a day care hospital on a regular basis although one lady (Mrs Gibb's sister) was taken three days a week to a rehabilitation/assessment unit for a period of two months.

#### DAY CARE IN DURHAM

Day care services offer a wide range of facilities and care to a variety of users. The aims of centres depend on users and providers and there is provision in this area by local authorities and voluntary bodies.

The aims of day care as identified by Goldberg and Connelly (1982) are to provide opportunities for social activity outside the home and secondly to relieve carers. Depending on the philosophy and orientation of the centre the secondary aim is functional improvement e.g. social skill of the elderly or rehabilitation, or day care in residential homes which can be a preparation for permanent care (Brocklehurst 1981).

The Adult Training Centres and schools for mentally and physically handicapped children provided respite to parents in Durham five days a week, and occupation and skill training for dependants, but in this



study such facilities were relevant to only 14 per cent of family carers (22:153). Of the total study population under one third (43:159) of dependants enjoyed some form of day care away from home and for the interviewed families the proportion was 22% (5:23).

As Goldberg and Connelly point out in reviewing the research on day care for the elderly, there is as yet no fully developed:

"... day care service, in the sense of a continuum from day hospital, for the treatment and rehabilitation of severely mentally and physically disabled people through day centres, for the maintenance of frail elderly people to social centres serving as recreational facilities for the more able bodied".

(Goldberg and Connelly 1982)

A recent Health Advisory and Social Services Inspectorate report (1987) noted that Durham is reasonably well provided with day care facilities, but these are both inappropriately and under used. Hospital day care facilities were positively geared to rehabilitation but essential follow up services were inconsistent.

Brocklehurst and Tucker (1980) quoted in Goldberg and Connelly (1982) interviewed a sample of 74 relatives, two thirds of whom said that their dependants' attendance at a day hospital had made a difference to them, giving them a chance to do shopping, and have relief from worry. However, relatives had little idea of what happened at the hospital and played no part in rehabilitation. The lack of communication which these researchers highlight was evident from the few people who had

experienced day care in the Durham study and exacerbated the frustration felt by families.

"She used to go to St. Mary's twice a week, for a day. In the end we stopped that. She'd make such a fuss and say she wasn't ready and you can't keep them (the ambulance drivers) waiting".

This brother caring for his sister was resentful of his position and found the tending required of him very difficult. His reluctance to get his sister dressed contributed to her losing the day care place but she had been unhappy there and was not responsive to rehabilitation:

"They make you knit dish towels and no one talks to you. I'm better off at home. I'm alright if I lie down in my bed. It's best not to go."

In a study of adult day care Carter (1981) found that those who were most disabled received less day care than the more able bodied and the provision of transport was a critical factor in this distribution. In Durham the local authority purpose built day centre for physically handicapped, capable of accommodating wheel-chair bound people caters, in fact, for many mobile elderly people because of restrictions on transport, among other factors. One disabled man of 35 years had his two days at this centre cut to one because the transport drivers said they could not manage his electric wheelchair.

Edwards et al (1980) noted that those in most apparent 'need' receive least day care. The inappropriate 'blocking' of some facilities and limited transport provision restricted the general availability of relief for carers of the most disabled and limited the time those who enjoyed the break were away from home (Flew 1980). Occasionally, however, inappropriate use of a service could benefit a carer.

"Well he goes to the stroke club one day a week. Its very good of Mr Oxley (CPN) to organise it because with his condition (senile dementia) he shouldn't be going to that. But its very hit and miss, it depends on the transport and if Mr. Oxley has got a space in his car". (Mrs Winter)

The stroke club was ten miles from Durham and run by a voluntary group. The patchy provision of day care facilities exacerbates the difficulties for those attempting to organise support for carers.

Day centres run by voluntary agencies, notably Age Concern provide valuable 'drop in' facilities and luncheon clubs for the elderly. Although inappropriate for severely disabled people at least one interviewed carer in the study was able to maintain social contacts at a luncheon club when relieved by a care helper.

The lack of communication between day hospitals and carers noted by Brocklehurst and Tucker (1980) was happily not a feature of the school and training provision for young disabled people in this study. The Adult Training Centre which Mrs Parker's sister had attended for 15 years shared a treatment programme based on rewards.

"Well when my father died I knew there was no way I could cope with this. She could surely get her clothes on right if we taught her. She doesn't like being asked to do much but she can. Like the toast she can make two pieces of toast and she's really proud of herself. At first I had wet beds every night, not now. And the centre they tell me about her table manners and we sort of work together. Like with the beds she can now go on the trip to Blackpool and she knows why she couldn't go before. The Centre's good like that."

The younger people attending the special school came home with a diary. This was appreciated by Mrs Stokes and Mrs Jacobs:

"It helps because if she'd had a motion during the day I know and I can reduce her drugs."

"It's important to cooperate on a care plan, after all, they are at the school for a lot of time each day and it is no good pulling against the staff unwittingly. He'd never make any progress."

Parents' greatest anxiety was connected with future care (Glendinning 1983) and plans for a special care unit attached to the school were being watched keenly.

#### DOMICILIARY SUPPORT IN DURHAM

##### Primary Health Care

The services referred to here are represented by the district nurses, community psychiatric nurses, community mentally handicapped nurses, health visitors and bath attendants. General practitioner services are also included.

Community nursing services are primarily patient centred, and the care provided is designed to ease the comfort of the patient rather than the primary carer.

Table 8.1 shows the provision of domiciliary support, nursing and welfare, to the survey population giving the household composition and gender of main carer.

TABLE 8.1

## PROVISION OF DOMICILIARY SUPPORT BY HOUSEHOLD COMPOSITION

Household type	Disabled people	Sex of main carer		Domiciliary nursing services including support visits	Domiciliary care service M.O.W. & H.H.
		No.	No.		
	No.	M	F	No.	No.
Living alone	25	6	18	17	21
Living alone with no main carer	2	-	-	2	1
Couples with main carer living away	4	2	-	2	1 private h.h.
Couples	46	21	23	30	17
3 generations	16	1	15	5	3 + 1 private h.h.
Siblings	8	2	6	6	2 + 3 private h.h.
Family - 16 year old children	24	2	22	3 + 1 private nurse	1
Family with adult children 16+	4	1	3	2	1
Dependent Parent(s) + adult child	15	3	11	5	4
Elderly dependent parent + married couple	12	4	8	6	2
Elderly parent + adult dependent child	3	-	3	3	2
<b>TOTALS</b>	<b>159</b>	<b>42</b>	<b>111</b>	<b>81</b>	<b>53</b>

\*Domiciliary nursing services includes bath nurses, health visitors, chiropodists and community psychiatric nurses, as well as district nurses.

\*\*Domiciliary services includes meals on wheels, home helps and social work support such as occupational therapists and social workers.

Nursing services attended 81 households to support and give specific help to a disabled person. This is 52 per cent of the families helped by Durham Community Care and slightly more than the number referred by the nursing services (46% see p. 93 ). In over half the households (47:81 dependants) the support consisted of getting a disabled person up and back to bed. Except for two people living alone the disabled people were cared for by elderly relatives unable to cope with the physical strain of lifting. About a quarter of the nurses' patients were helped to bathe and the same proportion received medical attention, dressings, drugs, injections. Additional support visits were made to one in five families (16:81).

Under-resourced domiciliary nursing services have to make care choices and the support provided by Durham Community Care frequently complemented the nursing service by getting patients up and putting them to bed at weekends and the evening when other nursing priorities took precedence.

Early morning care was required by only one family whose disabled member attended a day centre and required getting up before the nursing services were able to operate. However, seven further families received regular help to get a disabled person up and dressed one or two mornings a week. Help was required, usually at weekends, when the district nursing service had few staff and people who wished to be out of bed at a reasonable time were reluctant to wait for help from a nurse at an unspecified time. Each carer being supported in this way was elderly and unable to lift.

The 'back to bed' support given was designed to reduce both the risk of physical injury and the anxiety of the carer. Durham Community Care helpers regularly put 16 people to bed over and above those who had been cared for during the evening and put to bed before the carer came home. In about half of these cases the family had other support during the daytime and the relief of general strain and prevention of an imminent breakdown were the primary reasons for care. Most of the carers were elderly, others were themselves frail or disabled. Nursing expertise is not necessary to relieve such carers of frail dependants and support can be adequately provided by auxiliary staff or care attendants (Harrisson et al 1983).

The younger disabled - those under 60 years of age - figured only marginally in the district nurses daily work load (13 people). Two of these younger people lived alone and had regular nursing support up to seven times a week, but of the remainder only those with carers over 60 years of age or male carers received general nursing support (getting up, support visits). Where a young disabled person had a female carer the nursing service concentrated solely on dressings and medication. In the five cases where this situation pertained the disabled person was unable to perform any self care functions and had required total care for more than two years.

The families who were interviewed were generally well disposed to nurses who visited them. Borsay (1986) reports a similar response in a study in the Midlands. They were seen as providing a necessary service with very stretched resources. The main cause of problems stemmed from those limitations; that they did not visit as frequently as carers would like, for example, to get a patient up, or visit at

times convenient to the family. These were difficulties which arose when support was being provided which was not strictly nursing in character.

Nurse respondents in Harrissons and Ayton's (1981) study of the care of elderly people in hospital and the community considered there was "... no such thing as a 'non-nursing' duty" when in a home. However, pressure on resources leads to definitions of responsibility and priorities and a 'back to bed' service was a low priority. The implications for the families were physical strain, worry and at best inconvenience.

"Its worse at night time. It would be better to have a bath nurse and the auxilliary at night time and then put her to bed".

(Mr Frost)

Harrisson and Ayton (1981) refer to the work of Isaacs and Neville (1975) and rank in importance to patients the sense of loss which might be felt when losing control over every day activities. The most important activity for disabled people is getting up, then, going to bed, when they want to. This surely applies to carers as well, who have to rely on outside help.

"Well I'd be lost without them. Now she's lost the use of her legs. But I have to be up at about 7.30 a.m. to do the fire and that, to be ready for the nurses coming, whereas before I could lie till about 9 o'clock if I felt a bit tired. I have to have the room warm though, for them to bring her through."

This gentleman, and Mr Frost above, were caring for their wives.



Elderly women who were caring had help with non-nursing tasks. However no female carer under sixty years in the interview sample had any help with such tasks. It is important to differentiate between the types of help provided by community nursing teams because younger carers not only missed out on auxiliary services but there were also reports of lack of guidance with care of a severely disabled relative despite the nursing view quoted by Harrison and Ayton (1981) that "the essence of district nursing is to teach the family how to cope". Such help was particularly lacking with lifting and bladder care despite the assurance of government departments that "general advice is given to patients (and others) ... on health problems including those associated with incontinence" (DHSS 1981 'Growing Older').

The provision of nursing support was not a major part of this study but the interview data strongly indicates that female carers under 60 years with long term care responsibilities felt poorly supported by the community nursing service. Other carers, the elderly in particular, were satisfied although the support they required usually went beyond what local resources could meet.

Mr Stoner (p. 197) had a good relationship with the auxiliary nurse but was still required to get his wife to bed each night, often with considerable difficulty. This limited study confirms on a local level the need for auxiliary grade nurses within the authority, identified nationally by Keywood (1973) and Harrison (1983).

The apparent contradictions between day care policy and community care policy which carers highlighted added to frustration. A carer who reported that her mother was no longer 'fit enough' for the day hospital felt entitled to nursing care at home.

"Well, I've had a good few battles I can tell you especially with Sister W. You heard about the suppositories I suppose? She arrived at 3 o'clock - just when I would be expecting the boy home, - gave her one and walked out saying she was far too busy to stop. Well if Theresa (care helper) hadn't been here I don't know what I would have done. She was in a terrible state, covered all up her back it was (faeces). I really go out to work to employ a nurse for a few hours. She's qualified and comes for a few hours on a Friday, but when she's dirtied herself it takes two to clean her up and hold her up. Yet I've had to battle to get a nurse to help get her up three mornings a week ... and its not my husband's job, is it really ... If I was really ill there'd be a bed for mother next day, but because I'm coping they're saying 'Oh she's well looked after at home'. But by rights she should have a nurse everyday ... Sister W. just says 'Why don't you ask Durham Community Care to come in more often and get her up?'. They don't seem to understand."

Mrs Wright had many confrontations to recount in her attempt to get the support from all domiciliary services she felt were important. She felt strongly that she should have trained help and that no service providers from psycho-geriatrician to social workers had any comprehension of the pressure she was under (Mayer and Timms 1970, Sainsbury 1980). She accepted residential care was probably the only answer for her mother but demanded care of the highest standards. It is possible the respite care provision which enabled Mrs Wright to have some freedom reduced her mother's 'priority' status and perceived need for long term care.

"Perhaps if I left her on the Town Hall steps they'd do something they'd have to, wouldn't they? I think because Theresa's (care helper) coming in they think they've done their bit. Your scheme's probably keeping her lower down the list."

Over half the sons did not have their parents living with them, yet each of the elderly people was unable to perform at least one of the self care tasks (p. 159 ). There does not appear to be a correlation between capacity for self care of the dependant and relationship to carer in this study, in contrast to Wright (1985) who found clear sex differences between male and female carers in some of the personal tasks they had to perform for their dependants.

The small number of single sons in this study (3:11 sons) make such comparisons difficult but it was noted that those three (3:5 resident sons) were not adequately meeting their parents' physical needs, in the opinion of the referring agencies, and were resistant to offers of support. It is possible that social/medical agents who are predisposed to supporting male carers are most sensitive to a break down in such care. In the case of the three dependants referred to, their admission to institutional care was hastened by the 'break-down' in care provided by their sons. Where the parent lived alone, those with non-resident sons were more likely than those with non-resident daughters, to be supported by domiciliary services.

The support provided to families caring for someone with senile dementia was the responsibility of the community psychiatric nurse. During the period of the study one particular male nurse was giving outstanding support to these families. He was praised by families for his efforts to ease the burden of care in small practical ways,

sometimes bending the rules as when he slotted Mr Winter (p.209 ) into an after-stroke club, and for his understanding and patience.

"I mean Bob is lovely, and I've screamed at him and all sorts, I've been rude to him but he seems to understand and care more than what they do (hospital consultants). I don't think women doctors want to know your problems, they could do something if they wanted to. I know there's not a great deal Bob can do but he's very supportive."

Bayley (1973) noted that the opinions users had of a service depended on the relationship of a family with a particular worker. During the time Mr Oxley was working with clients in Durham their opinion of the service was high even when residential places being sought were not forthcoming.

This community psychiatric nurse was providing what Goldberg and Connelly describe when talking about social workers as:

"... a kind of maintenance function by recognising and understanding the client's chronic illness and burdens and in a way sharing them".

(1982, p.87)

Recognition of the enormity of carers responsibility can go some way to helping carers carry on. Such recognition can help restore carers' self esteem by meeting their 'safety' needs (Maslow 1943). Often the 'expert' is the carer and this should be acknowledged (Glendinning 1983).

"This doctor from ... said 'the thing to do is walk away from it' but I said 'that's all very well but you haven't had it for months and months 24 hours of the day'. I mean, you can't just do that, you can actually tell them more than they know",

or

"I've lost faith in doctors, I've no faith in them at all. After seventeen years I know what these drugs will do. I dread to think what will happen when I'm not here, they'll give her anything just to keep her quiet."

Recognition of carers' responsibilities and acquired knowledge should be matched by general practitioners and specialists such as geriatricians being prepared to explain a coherent philosophy behind decisions concerning patients and relate these to carers (Hewitt 1970, Isaacs 1981). In the view of Cartwright (1973) however, most general practitioners were unaware of the inadequacy of services in the community and the pressures experienced by carers. It is likely that more understanding may now exist among general practitioners as with the wider population.

The two women above had very unhappy experiences of medical, particularly hospital, care. Yet this was not always the case and one couple had moved from Weymouth to be near the specialist care they felt was best provided in Newcastle.

#### General Practitioners (data available on 114 families 72%)

General practitioners did not make referrals to Durham Community Care. Their role as front line observers of carers and 'gate keepers' to other services (Glendinning, 1983) would make this surprising were it not for the close cooperation between Durham practices and community nursing services. The schemes covered five practices and carers' views

of the attention and support they received from their doctor varied from "only comes when I call him" to "makes a monthly check at the house." Locally, general practitioners are paying particular attention to the elderly and their carers appreciated the doctors' concern.

The majority of families however had neutral feelings about their doctor. They reported that they received visits as and when they were required and considered the attention they received was satisfactory.

There is of course, as Borsay (1986) points out, a 'social ethic' against bothering the doctor. Patients will go to great trouble to attend the surgery and never expect a home visit:

"No the doctor doesn't come. He'd certainly never come as a matter of course, so to speak. We both go over to the surgery if we need to. We can get a bus and if its a good day we can just about walk home".

Only 14 families reported their doctor called without being requested and half of these had visits more frequently than once a month. Invariably the regular visiting was associated with a change in the health of the dependent person. Four families expressed very positive feelings towards their GP and the same number made equally negative comments even to the extent of refusing to consult him at any time. Blaxter (1976) noted a strong relationship between the existence of social and other problems and a poor relationship with the medical profession in her study of adult handicapped people. Such observations are supported in this study.

The Association of Carers (and private communication) recommends its members to consider seeking a doctor who does not also care for the

dependent person. Often the needs of the carer are over-looked in the medical pre-occupation with the sick or disabled person and the carer handed sleeping pills.

Mr Frost had been experiencing exhaustion and dizziness for many months:

"The doctor's not really bothered so long as I'm sleeping (with the pills) he thinks he's doing as much as he has to for me."

But Mr Grayson's request was differently received:

"In Coventry when she first took bad the doctor gave me some good pills and I got my sleep. It was probably the only way I got through, so I went to the doctor here about some pills and he said, 'You won't get sleeping pills from me'. Lily's got sleeping pills and I could have some of Lily's occasionally. He said 'No. But you can have half about once a month'. Maybe just as well."

#### Social Services Department. Domiciliary Services

The Local Authorities Social Services Act 1970, embodied the recommendations of the Seebohm report and in 1971 Social Services Departments (114 in England and Wales) were created out of the Children's and Health and Welfare Departments. The scope of such departments are wide, with permissive and mandatory responsibilities for children and families, the elderly, mentally handicapped people, physically handicapped people and the mentally ill.

It can be argued with some justification that primary health care teams have responsibility solely for their patients and when resources are limited care choices have to be made which favour the sick and

ultimately those who do not have family support. Ideally however, domiciliary support services should have a wider preventative perspective and aim to maintain the household, even where there is a family carer (Goldberg 1981).

Table 8.1 (p. 211) shows the distribution of help to families. Domiciliary services, provision of a single service or a combination of home helps, meals on wheels, therapy and social work support was provided by Durham Social Services Department to 53 (34%) households, about one in five of these had both a home help and meals on wheels service. Five families employed private domestic help.

The services were available almost exclusively to households where the dependant was over 60 years of age, the five exceptions being the two disabled people living alone without a carer, one young man looked after by his frail parents, a man cared for by his non-resident sister who was also disabled and a young woman cared for by her working husband.

In households with an elderly dependant services were divided between elderly people living alone whose carers were working or frail - 21 dependants including two couples had a home help and five of them also had meals on wheels - and lone carer households where the carer was also frail and elderly. Of the lone carers receiving domiciliary services men outnumbered women two to one.

Only two female carers under 60 years of age living with their dependant (a parent) had domiciliary support. Both were working full time and their elderly parents received meals on wheels. The complaint



of carers nationally, that they are used as a resource is borne out by this small study, and again it shows women in particular shoulder a big burden.

### The home help services

The National Joint Council for Public Employees has agreed broad guidelines for the duties of a home help. These include; day to day cleaning (not spring cleaning) washing and ironing for the invalid or children in the household, inside window cleaning, cooking and shopping (Marks 1975). They may not do; nursing, washing walls, work for lodgers, guests or other adult members of the household, gardening or 'sitting in' duties. Hunt (1970) in her study of the home help service in England and Wales revealed that over one third of home helps thought their 'cases' needed more time and their job description prevented them doing many tasks which they felt were necessary. Both Hunt and Marks record that home helps reported doing unpaid work to meet the needs they felt were not being met in the allocated time, and Howell, Boldy and Smith (1979) found 25% of home helps providing extra support.

The home help service focuses primarily on the needs of the elderly and young families. Hunt (1970) points out that there would need to be a 50 per cent increase in the provision of home helps if households with seriously handicapped members other than the 'housewife' were taken into account. The exclusion of families with such disabled members from the general policy of allocation means that households with an able-bodied carer do not come within the remit of the service.

There are moves in many parts of the country to re-assess and widen the job description of the home help (Davies 1981, Challis 1985). to a 'hybrid' worker. Such proposals are of benefit to elderly dependants and carers but younger caring families do not receive such detailed attention and innovation is patchy (Ferlie 1980).

Borsay (1986) notes Sainsbury's (1970) findings of 'disturbing complacency' about the unsatisfactory provision of services, particularly with home helps failing to visit when expected. At a local level there seems little change over the years in organisers' perception of the urgency of this problem to the recipient or their ability to provide necessary help to families. Goldberg and Connelly (1978) observed the excessive work load of many home help organisers, to which is added, locally, a discrepancy between the perception of the service being provided in the view of senior domiciliary services personnel and the home help organisers who acknowledge that they cannot insist that individual home helps work anti-social hours (personal communication).

For many families the resultant inflexibility and/or unreliability of the home help service made it irrelevant. Families felt it could not guarantee the aid to coping they were looking for and this low expectation affected demand (Harrison and Ayton 1981).

"I had a home help for a while but really I could do it better myself. You had to go round after them doing it all again. I pretty soon decided they were useless and gave them the shove." (Mr Frost)

"I do it myself. I can manage. I have a routine and I've got used to it. The good thing about the girls (care helpers) is they'll see what's needed and get on with it, they're not restricted by rules. Last week Ann said leave the ironing and today when I came back from the garden there it was, all done beautifully." (Mr Brown)

Mr Stoner also felt he could manage without a home help:

"These places don't justify it and I don't want me shoppin' done. I like to get out. It does me good these days when Theresa comes on a Tuesday and a Thursday I can do it all then and I get me exercise."

Mrs Winter was the only female carer in the interview sample to have a home help. She was in her seventies and had recently been ill:

"I have a home help twice a week for one and a half hours. She's been coming for the past six weeks. I decided to have a one 'cos I had an angina attack and then I got shingles and then I got 'flu. John (husband) went outside and brought a man in and he offered to take a message. He didn't know what to do but he knew I wasn't right so he did the best he could - fortunately the man was respectable and understood what John was like! The nurse called, she called the doctor and he got on to my brother in Yorkshire. His wife was away but she came up from Somerset in one day and she stayed till I got put right. So after that I thought I better have some help, at least with the housework."

### Meals on wheels

A number of studies in recent years have looked at the domestic capacities of recipients of meals on wheels. Estimates vary from 50 to 75 per cent of meals recipients being house bound but reasonably mobile within the home (Goldberg and Connelly 1982).

It is argued, as a justification for meals delivery that a surveillance function is effected but Johnson et al (1981) consider this to be of

limited value as most recipients are well supported socially. They also stressed that satisfaction levels should be seen in context. For the elderly in particular, low expectations and gratitude predicate positive verdicts (Martin 1986).

Delivery, of itself, is of questionable merit if quality and nutritional value are low. Borsay (1986) quotes an Age Concern report (1981) and J.R. Kemm (1979) who bear out anxiety about nutritional value of the meals. Mr Stoner (p. 197) simply felt the size of portions would be too small.

Another carer, whose sister received meals on wheels pointed out the limited value of delivery to some confused elderly. She said:

"She wouldn't eat them unless I was there. I had to spoon feed her and if I hadn't gone everyday they would have simply piled up on the door-step".

That elderly carer, like a daughter looking after her mother relied on care helpers from Durham Community Care to visit her dependant at meal times to ensure that the meals were eaten.

Thirty two per cent of the recipients of social services domiciliary care had meals on wheels (17:53) and two of the interviewed families. Those two families appreciated the service. Terry's mother and father found that their mornings were less rushed twice a week. They had recently started receiving meals because Mrs Cole had broken her arm but a home help was not offered (she believed) because their daughter lived close by and helped out. Mrs Dale also found she benefitted because of the meals delivery:

"I get very tired at the end of the day. But I'll take things step by step and we have the meals on wheels two days. And, as I say that's a help 'cos if I'm busy with George and time's getting on I don't need to get worried about not doing the lunch".

None of the male carers interviewed (6:23) had meals delivered. They did not claim to be good cooks but the rumours they had heard about quantity and quality deterred them from trying something new.

Clearly meals on wheels could have a benefit to overworked and frail carers as a supplement to other domestic arrangements. A pre-occupation with the domestic functioning of the elderly recipients may be limiting the possible benefit of ready prepared meals to carers.

#### Social work services

Although social work may not be immediately seen as a domiciliary service it will be considered here, very briefly, because to make contact with carers social workers must visit them at home as their caring tasks keep them confined with their dependant. Goldberg et al (1970) looking at welfare officers' screening the elderly noted that they were not 'sensitised' to 'family stress' or able to recognise probable breakdown in informal caring arrangements. The elderly certainly are not the most popular client group for social workers and carers, perhaps, do not offer the challenges which accrue from working with children and offenders. Social services departments' responsibilities to carers are at best permissive and the orientation towards the dependent person pushes the carer to the margins.

Changes in management style and organisation towards integrated services at a local level (Young 1985, Bayley and Tennant 1985) are

being tried in different parts of the country. The shift in social work orientation, from casework to intermediary and provider of other services for the client through a community centred approach, is also gradual and can be seen in 'patch based' social work (Hadley 1981, Hadley and McGrath 1981). It reflects the demands of community care (Barclay Committee Report 1982) and the intrinsic value of informal care systems described by the Wolfenden Committee (1979). The role of family carers needs to be central to social workers' approach to work with dependants and their families (Tinker 1985). Rowlings (1981) notes that social workers tend to be called in when caring systems have broken down because carers do not usually refer themselves for social work help. She advocates support groups as an attempt to alter the traditional reactive practice within social work and aid carers' recognition of the limits of their capacity to care. Such groups have been arranged in Durham for relatives of elderly senile dementia sufferers. Unfortunately carers who had no one with whom to leave their dependant could not attend. From the perspective of a carer such ironies are common place and lead to feelings of dissatisfaction with social services personnel (Wade et al 1983).

The overwhelming impression gained from this study, is that carers' views of social workers, as a particular group of social services personnel were confused. McKay et al (1976) investigated the subjective perceptions of consumers of social work services and found that clients often came to social services departments with unrealistic expectations. Many of these people were elderly. Social workers thought clients expected to be able to discuss personal problems whereas consumers hoped for practical help such as aids, services, clothing and bedding.

Miss Hyde who had suffered several breakdowns and had been a mental illness hospital in-patient was being supported by a Community psychiatric nurse. She still felt the need to share more fully, her responsibility for her mother.

"We had a chair from social services for her, and the nurse brings the pads. I get my injection twice a month but really we would like a social worker. Someone who would listen, they could help with the housing too perhaps."

She clearly saw advocacy as a part of a social worker's job as well as case work support. In one of the earliest consumer studies of case work Mayer and Timms (1970), when highlighting the discrepancy between the expectation of clients and social workers, noted the dissatisfaction of working class clients with a case work approach when they knew they wanted material help. They concluded that without an understanding of the expectation of clients there is little chance of an improvement in the service. Mrs Stacey and Mrs Wright felt their social workers had no idea of their problems:

"They come and sit there looking uncomfortable and when you ask them to get you a cushion or whatever they say 'yes' and that's the end of it."

"They all sort of come in an waff about but nobody actually does anything. I don't want anybody to say anything I want them to do something."

Mr Frost felt the same but his complaints extended to the Social Services Committee and the hospital:

"I asked the committee for help to get some action with Jane. The O.T. didn't do anything for ages and when she came she said 'we'll see'. I don't know. Social services, if you make a fuss they all come at once wanting to know what they can do and then when you tell them they go away and that's the last you hear of them".

Clearly Mr Frost was in need of practical help which was not in the remit of a social worker. Mrs Cole, Terry's mother, had been engaged in a long running battle with the department about his exclusion from a day centre. Social workers had visited her.

"They've come about the day centre, but they don't know what to do. They're full of promises but that man (the officer in charge) is one of them. They're not able to do much about him. The nurses, they don't have time to chat."

Regular support visits to this household and a more productive advocacy role might have been welcomed here. Younger carers appreciated the knowledge and shared expertise of special school staff and seemed to have a clear understanding of the responsibility of personnel. One such carer made the following perceptive comments about her social worker. Mrs Stokes said:

"When the social worker comes she says 'Are you alright?' and she means 'Is Dorothy alright?' Do we need any aids, equipment and that sort of thing? ' But she did help with the sling. She put a lot of work into getting me the right one."



Welfare aids and adaptations (data on 134 families 84%)

More than 80 per cent of all families had some aid in their homes provided through nursing or social services departments, to help them in the care of their dependant. Toilet and bath aids e.g. commodes, hoists and bath rails were the most common with wheelchairs mentioned by twenty per cent of families. Families did not seem to have difficulty in obtaining basic aids which did not involve structural alterations to their homes. However, delivery was not always followed with an explanation on use and the interviewer was told by several carers that 'hardware' piled up in their home because they did not know the best way to fix a tray or operate a chair and 'no one' came to show them.

Borsay (1986), in reference to studies on the provision of aids to both the elderly and physically handicapped, notes that as many as a third of the aids issued to help with bathing and toileting are never used. She argues that such high levels of non usage indicates that small alterations are not always in tune with disabled people's housing requirements and what is usually required for example is not a bath seat but an easy access shower (Blaxter 1976). In the opinion of Wade et al (1983) widespread ignorance of the variety of aids available and their source of supply contributes to their under exploitation. A problem which is exacerbated by social workers' failure to mobilise promised resources or maintain contact with those who might be experiencing difficulties.

The initiator of the Durham scheme wrote in 1986 about delays in acquiring aids:

"After my husband's funeral, two ambulance men arrived to take him twenty miles to the artificial limb centre to be assessed for a cushion that we had been trying to get for months."

(Brady 1986)

Mrs Eden waited many months for a stair lift:

"I think in these council houses they don't like to mess them about so they hang on with one and another coming, perhaps they think because he's got that illness (cancer) he won't need it for very long so they'll wait and see if he dies".

Others have similar problems to recount but occasionally could circumvent the red tape:

"All I wanted was a seat for the bedroom, one that he would not topple out of but it went on and on one after another coming, and in the end I heard of a person who'd had one and died and I went straight to them and got it. I let the social services sort it out afterwards."

(Mrs Storey)

Borsay (1986) considers health and social services personnel label the victims of disability (and their carers) as incapable. This tempts expert helpers to exploit their powerful positions and arrange services (or aids) to suit themselves, as Mrs Eden felt happened to her husband and herself. None of the interviewed families had satisfactory stories of modification to their home although it was easy to get a wheelchair.

Two families had asked the Social Services Committee for help with installation of central heating. Neither application was successful.

"We were on Social Security and he couldn't keep warm. Four blankets and an eiderdown and hot water bottles and he was still cold so we applied for central heating and the O.T. came and saw him for five minutes and the answer came back - no we couldn't have it. If Social Security says you can't have, you can't have then if they say yes you have to wait ages and have only what they want so when I got left a bit of money from my cousin I went ahead and got it put in myself. Same with all the bannisters. I've bought the special cushions and this table. I'm like that if its necessary, I'll go and buy it whether I can afford it or not, if its going to be helpful."

"I asked the Social Services Committee for a loan to put in some central heating. They said I should go through the Bank or Building Society, but I can't afford the interest rates, so we've had to use all our savings. Now we've nothing to fall back on. But she was always cold before."

### INCOME AND HOUSING

The assessment interview, namely the first visit the organiser made to the home of a referred family, varied in depth and content depending on many factors including the nature of the dependant's disabilities, the relationships involved, the source of the referral and the level of anxiety in the carer. On the basis of information that was available to the researcher from these interviews some comments can be made about financial support received by the families and their housing circumstances.

#### Financial Situations (data available on 78 families 49%)

The financial cost of caring has been the subject of much national argument. Opening a debate in the House of Commons on 1st May 1986 (Hansard) Michael Meacher, Shadow Health Minister, stated that carers

save the country £5,000 million pounds a year. The opportunity cost of constraints on carers' employment (Nissel and Bonnerjea 1982, Baldwin and Glendinning 1983) must make that figure appear conservative. The concession to carers in the form of the invalid care allowance could not be assessed with respect to this survey but the difficulties described regarding the attendance allowance suggest that claiming both benefits and allowances is a traumatic experience.

"We were turned down at first for the night allowance. It seems that happens automatically and you have to appeal. Well really we'd just rather not bother. It would help with the heating though."

"I did apply but you have to wait six months and by the time they came to assess him my husband had died. I just stood at the door and cried."

Only 35 (35:78) reported receiving the attendance allowance. A further 13 per cent (21:59) were 'being assessed' or had 'applied'. Five refused to apply on the grounds that they did not want to be paid for 'doing their duty' (Blaxter 1976). Financial difficulties are frequently faced by carers. Receipt of full entitlement would have reduced some of the pressures.

Lack of knowledge of entitlements and how to go about seeking help was one of the reasons behind the creation of the Association of Carers. The comment below illustrates carers' needs for advice and support at an early stage and quick decisions on financial aid.

"My husband had finally to go into hospital (last two weeks) because I was no longer able to cope. If I had received more help it would not have been necessary for him to die in hospital but in his own home ... Also during his illness I had a lot of extra expense e.g. coal fire on night and day, but I did not even know of the attendance allowance until it was too late."

## Housing

Unsatisfactory accommodation, lacking basic facilities or appropriate adaptations can lead to disabled people being admitted to residential accommodation (Wade et al 1983) and if they remain in their own home to seriously restricted lives. (Sainsbury 1970, Harris 1971, Bristow 1981, 1986, Borsay 1986).

"He had to stay upstairs all the time. Except at the weekend when two men from the (Salvation) Army came and carried him down. It meant so much to him to be with us and see what was going on. The lift was the only thing we ever asked for and it took nearly a year to be put in".

Of the families interviewed, 40 per cent (9:23) lived in bungalows, the majority local authority owned. All but two of these dependants were wheelchair bound and clearly would not have been able to manage stairs. The effect on daily living, when the only sitting room is also the dependant's bedroom is disruptive to the family and demoralising for the disabled person who has no privacy (King 1974, EOC 1980).

"There's nothing else we can do. Terry has his television in that corner but his dad and I can't sit in the back kitchin' all the time, we have to share the room but its not really fair on him is it?"

Stair lifts were fitted in two local authority houses but the waiting time for such aids caused great hardship. The delay in getting grants and planning permission for alteration to their homes did not give owner occupiers any real advantage over council tenants and they could not benefit from the 'city care' warden alarm scheme, although there are plans to extend the scheme to the private sector. Elderly council tenants are linked to a central 'station' and pull cords in the home

will alert a mobile warden if a tenant is in difficulties. Approximately one fifth of families were living in accommodation with a warden either on the site or on call (34:155) which included all people in the study who were tenants living in a council bungalow.

As Fox (1981) points out the very success of sheltered housing is one of its drawbacks. He suggests that because elderly people do not wish to move on to the next stage of care the role of wardens needs to be re-assessed and while recognising that they are concerned with helping people live independently they should be part of a support service to keep the elderly safely in the community. Such services are provided in privately owned and non sheltered housing schemes (Midwinter 1986). Etzioni (1976) has argued that for elderly people without relatives group living with their peers is likely to provide them with opportunities for socialisation and aid their independence. Experiments in housing schemes in Holland, however, are based on the opposite philosophy of generational integration (Hanning 1985) to provide support for elderly people. The housing needs of the very old will become an increasingly prominent element in the debate about their care.

Younger disabled people housed near the elderly may not be happy when the expected reciprocation of care central to the scheme for elderly people described by Hanning does not materialise.

In one particular case in the present study the bungalow on a sheltered housing development was satisfactory internally for a severely disabled man suffering from multiple sclerosis, but the location of his family

with a teenage daughter among elderly residents caused a great deal of friction with neighbours. More sensitive placement of this family might have avoided a great deal of distress.

## CHAPTER 9

### EVALUATION OF THE SCHEME

#### INTRODUCTION

The term evaluation implies the measurement of outcome against certain criteria. It requires a prior understanding of clear aims and objectives but as Patton (1986) points out, goals are often 'fuzzy' and can only be measured by using 'soft data' which is less precise than quantitative measures. Evaluation in the field of social welfare therefore, where profit and production rates do not figure in the balance sheet, requires an approach which is primarily qualitative not quantitative. Moreover, as Goldberg and Connelly state:

"Evaluation is in some sense a matter of assessing the value or worth of an activity or an object, but if this is accepted it inevitably follows that there is no objectivity in evaluation. 'Value and worth' are essentially subjective judgements which will vary ..."  
(1981)

(Goldberg and Connelly, 1981)

A failure to state the value base of the evaluation, however, usually means that the criteria on which the judgements of worth are made remain hidden (Burton 1986). Once the values are stated, it is possible for service goals to be specified more precisely and evaluated.



Goldberg and Connelly (1982) identify four elements in the evaluation process:

- an identification of aims or goals
- a definition and assessment of needs
- a description and monitoring of input and
- a measurement of outcome.

A valid assessment of outcome is only possible if needs, means and goals are understood, even though goals are often 'fuzzy' (Patton 1986).

The goals of Durham Community Care were to:

- a) Identify carers of frail elderly and handicapped people living at home,
- b) offer support to carers by providing respite from their responsibilities while maintaining the disabled person at home and thus,
- c) improve the quality of life for carer and dependant by extending the choice of care options available for families and,
- d) delay or prevent admission of disabled people to institutional care.

While the first two aims and objectives are precise the notion of improvement in the quality of life requires an assessment of subjective reactions to the intervention. A consumer response is therefore an appropriate form of 'soft data' and best collected in interview.

The final and tentative goal of the scheme was to delay admission to institutional care by supporting carers who wish to continue caring. Without a control group success in achieving this goal has been the least easy to judge. It is ethically unacceptable to withhold care from a group assessed to be in need but the alternative of evaluating different forms of treatment (Reid and Hanrahan 1981) in an experimental way was not appropriate to the aims of this study.

It is argued that evaluation requires a 'pluralistic' approach (Smith and Cantley 1985) which can explore and explain an institution from a variety of perspectives using different methods to explore different aspects (Patton 1986).

A variety of methods of evaluation were used to assess Durham Community Care. The opportunity to monitor the scheme and participants over time provided a 'longitudinal evaluation' (Patton 1986). The 'assessment of need' was addressed in the process of selecting clients (Bradshaw 1972, Cuyler 1976) and as a 'descriptive study' it could provide a base for further research of domiciliary respite provision (Goldberg and Connelly 1982).

The 'effectiveness' of the service was considered in terms of its success in meeting criteria important to the families.

Effectiveness is the attainment of objectives through tasks that are merely means to ends (Bevan et al 1980). The objectives of Durham Community Care involved the provision of care helpers to relieve carers of care related physical strain and worry and enhance the horizons of carer and dependant. McGrath and Hadley (1981) consider the

measurement of effectiveness to be fraught with difficulties over identifying the criteria of judgement. The choice of criteria necessarily implies a point of view. This problem was recognised and from a 'value oriented' perspective an examination of the relief provided highlighted three primary issues as shown in Figure 9.1.

This chapter first considers the effectiveness of the service provided to carers in term of: reliability, flexibility and continuity.

Each had an impact on the well being of users and both short-term and long-term implications for users, management and staff. The effectiveness issues are 'treatment' or delivery issues reflecting three further areas which became apparent during the evaluation and are discussed in turn:

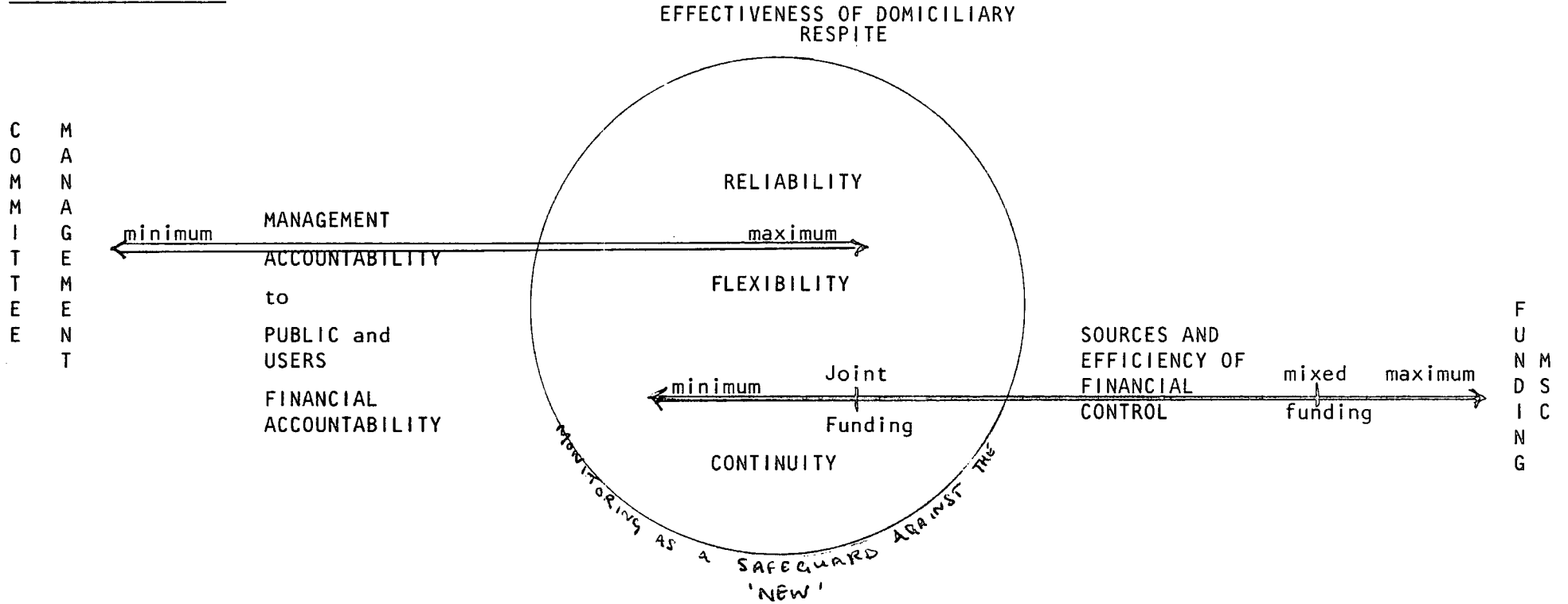
- accountability
- funding
- 'Safeguards against 'The New' (Goldberg and Connelly 1982)

These overlapping areas provide a framework for the chapter.

Figure 9.1 illustrates the interaction between the accountability of the management committee to the public, the users, funders and referring agents and the constraints of the funding source on the scheme. It is suggested that the greater the accountability of the management and the weaker the influence of the funder the greater the effectiveness of the service in terms of reliability, flexibility and continuity.

Figure 9.1

EVALUATION ISSUES



The EFFECTIVENESS of the Scheme is influenced by the level of management accountability and funding control. The greater the accountability of the committee to users and the public and the lower the MSC financial control the greater the reliability, flexibility and continuity of the service.

The chapter concludes with some observations on the role of the researcher.

## EFFECTIVENESS

The impact of the service on users can be viewed from a number of perspectives. The view point of the carer, the dependant, the service provider and formal agencies will be noted in considering the issues and are shown in Figure 9.2.

### Reliability

The reliability of a service is an indicator of management's values and respect for families. The importance families placed on this characteristic is clear:

"When they come week in week out you know at last you can make some plans and she looks forward as much as I do to the break".

The dependency of families as a result of an effective service has long term planning implications for management. Short-term management issues resulting from the value placed on a reliable service delivery concerned the selection, training and disciplining of staff and monitoring of care standards by the organiser. The stress on reliability highlighted employment differences between the management committee and the MSC agent whose concern was with maintaining individuals in employment rather than the quality of the service they provided to a vulnerable group of people. The short-term and long-term implications of the moral responsibility of the management committee and the funding dilemmas are considered later.

Figure 9.2

EFFECTIVENESS ISSUES

IMPLICATIONS FOR:	RELIABILITY	FLEXIBILITY	CONTINUITY
DEPENDANT AND CARER	<ol style="list-style-type: none"> <li>1. Security</li> <li>2. Encouragement</li> <li>3. Possible dependency (on care helpers)</li> <li>4. Standard of care</li> </ol>	<ol style="list-style-type: none"> <li>1. Responsiveness to changing needs</li> <li>2. Confidence in scheme</li> </ol>	<ol style="list-style-type: none"> <li>1. Anxiety</li> <li>2. Fear of loss</li> </ol>
REFERRING AGENCIES AND PUBLICS	<ol style="list-style-type: none"> <li>1. Credibility</li> </ol>	<ol style="list-style-type: none"> <li>1. Credibility</li> <li>2. Reliance on service provision (gap filling)</li> </ol>	<ol style="list-style-type: none"> <li>1. Reduction of disposal choices</li> </ol>
FUNDING AGENT	<ol style="list-style-type: none"> <li>1. Credibility</li> <li>2. Conflict with management e.g. over conditions of employment for care helpers</li> </ol>	<ol style="list-style-type: none"> <li>1. Conflicts with MSC e.g. over rules on working hours</li> </ol>	<ol style="list-style-type: none"> <li>1. Budget planning</li> </ol>
MANAGEMENT AND STAFF	<ol style="list-style-type: none"> <li>1. Selection of staff</li> <li>2. Employment conditions</li> <li>3. Training</li> <li>4. Standards of care</li> <li>5. Discipline</li> </ol>	<ol style="list-style-type: none"> <li>1. Maintenance of staff morale</li> <li>2. Training</li> </ol>	<ol style="list-style-type: none"> <li>1. Moral responsibilities</li> <li>2. Funding issues</li> <li>3. Contingency planning</li> <li>4. Training</li> <li>5. Staff morale</li> </ol>

### Flexibility

The responsiveness of the scheme to changing needs was appreciated by families and led to increased confidence and dependence on the service.

The versatility of the service, while strengthening the good name of the scheme, laid it open to manipulation. Referring agencies, notably social service personnel (social workers and home help organisers) and district nurses referred families, who elsewhere might have been the concern of their own services. This was especially true of elderly people requiring meal preparation at weekends or putting to bed. Durham Community Care filled gaps in local services which should have been covered by statutory provision.

The funding agency restricted overnight respite care after 18 months of operation. This directly affected the flexibility of the service. A further example of constraint on management was the eligibility criteria for potential MSC Community Programme (CP) employees. People who have been unemployed for 12 months prior to appointment and in receipt of state benefits are unlikely to be car owners. The organiser, therefore, was obliged to use those few care helpers with cars for late night and early morning working putting more pressure on them to maintain flexibility to families and thus adversely affecting staff morale.

Particular emphasis was placed in training on the need for care helpers to respond appropriately to the situation in each house. The following comments illustrate the willingness of care helpers to vary their

activities and the reliance of the families on the scheme.

"Mind, the girls (care helpers) are wonderful. They're all the help we get apart from the nurse to get her up and Stephen says "My, me mam gave those girls a run around tonight, do this, do that;" and I get cross as people like us don't get much and you should keep them sweet so that they don't get fed-up, but the fact is when Alison comes in she asks what Jane wants, "Does she want a bath or a massage or the bed changing?" they like to help and have a go at anything". (Mr Frost)

"It started as one evening for the carers Support Group, but I wasn't interested in the last talk but Mrs L. (organiser) said Ann could still come. She said "you go out and enjoy yourself" so I went to the club and it went on from there and when the wife goes into hospital ... they help take her ... and I have time for the garden. I like the routine but nobody minds if you want some extra." (Mr Brown)

### Continuity

The scheme was proposed and funded as a pilot project initially for one year. After six months it became apparent from the reaction of consumers and the rate of referrals from all sources that it was effective in meeting a previously unmet need.

Despite understanding the trial nature of the scheme families became very dependent both on the relief and the individual care helpers.

Informal reaction from statutory agencies reflected concern about the possible reduction of disposal choices for social workers and district nurses and a willingness to acknowledge the inadequacies of statutory provision. The particular features of the scheme which earned praise were the qualities and training of the care helpers.



From a management viewpoint the problem of continuity presented five related areas of difficulty. These were:

- a) the moral responsibility to provide support,
- b) the decisions required over choice of funding proposals,
- c) the formulation of contingency care plans for families,
- d) the maintenance of staff morale as contracts came to an end,
- e) the maintenance of a service during periods of staff change and training.

The long-term support of families required both decision making on funding and contingency plans for the care of families in the event of failure to find financial backing.

The search for alternative funding failed and re-application for MSC backing became the primary contingency plan. A slight reduction in acceptance of referrals towards the end of the first year combined with forging links with a voluntary sitting group and alerting agencies to the uncertainty was the extent of the planning against non-continuance. The management committee was confident that the MSC agent would renew the scheme for a second year provided the cost was within its budget.

A more serious challenge to management, both the organiser and the management committee, was the maintenance of staff morale as individual care helpers came to the end of their contracts. Feelings of loss at the end of the first year were deeply felt by care helpers and the difficulty of maintaining a service over a period of staff change as well as training new staff increased the anxiety experienced by families.

The following interview extracts illustrate the loss families were feeling at the end of the first year.

"They're marvellous, for the girl's sake I wish it were permanent. You know you get used to the girls in twelve months, and then you've got to start with all new ones".

"Richard\* was a great miss. A good help and a friend. He used to take David out and he enjoyed those outings".

"We were sad to see Richard go. He liked to have Richard, it was man to man and better for him. Its the toileting, its awkward with the girls".

"She gets on very well with the girls, they are of an age group that suit her (40-50 years), but really continuity is the best way 'cos they get into the way of doing things, and they come in and straight away start doing things. I don't have to show them what to do".

"Terry's confident with her. She's marvellous, we're really worried about losing her. Will we get somebody as good? She knows the routine. You don't need to tell her anything and she's always so cheerful, even at seven o'clock on a morning".

"My mother needed someone to take a personal kindly interest in her individually, so that she could enjoy the things of which she is still physically capable but quite unable to organise ... The Community Care helpers brought her a special gift - a boost to her self respect. But continuity was important - if the care helpers changed the help was less effective".

"It seems such a shame when you get used to people and they have to change. You trust them and its a shame they can't carry on."

The implications of continuity for the funding agent involved budget proposals and the need to 'sell' the scheme to the MSC as falling within the remit of a Community Programme. The MSC CP agent (The Boys

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\*Male senior care helper in year one. No men were employed in year two.

Brigade CP Agency) could not agree to re-fund the scheme until Durham Community Care had confirmation that no other sources of funding was forthcoming and secondly its own overall budget had been granted by the MSC.

The effectiveness of the scheme was adversely affected by the funding conditions.

### ACCOUNTABILITY

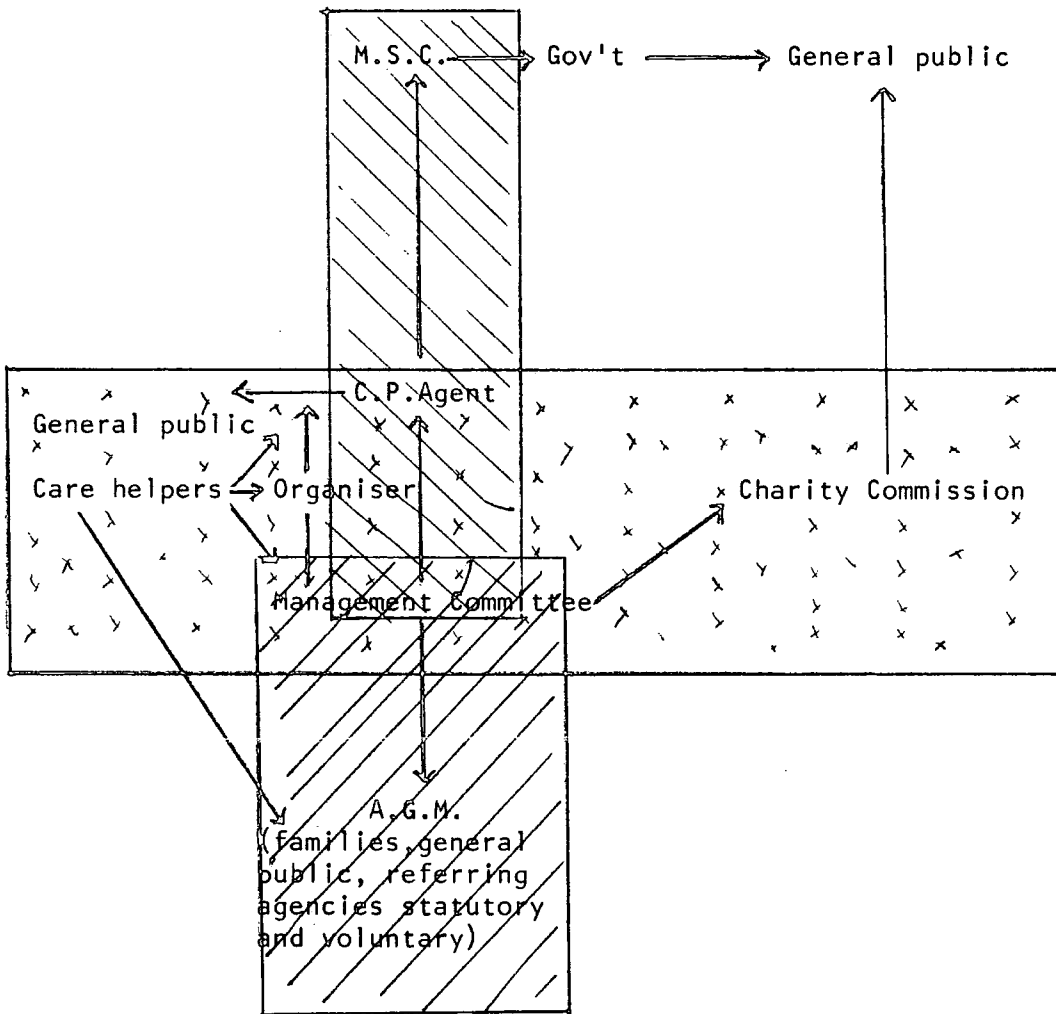
Information and monitoring are pre-requisites for the preparation of any account. The subject of the account and the audience for which it is designed influences the method and content. The necessity of accountability rests on the development issues raised in Chapter 3 which are ideological, political and technical. These issues not only reflect the need for accountability but can be partially summarised through looking at the process of accounting. There is overlap between the issues raised in the development of the scheme and also in the three areas of accountability; financial, public and user. For ease of description each area and its comparable developmental issue will be discussed. Figure 9.3 shows the actors involved.

#### Financial Accountability (Technical Issues)

The use of Manpower Services Commission funds to finance the pilot scheme had wide repercussions. As can be seen from Figure 9.3 the CP agent was accountable to the MSC and the implications for the management committee revolved around keeping within budget and long term plans to avoid dependence on annually allocated and possibly

Fig 9.3

ACCOUNTABILITY TREE



Key



financial/  
technical  
issues



user accountability/  
ideological issues



public accountability  
political issues

non-renewable sources of funds. The technical solutions employed included fund-raising which in turn meant the committee was accountable to the Charity Commission because of the scheme's charitable status.

The employees of the scheme were also responsible to the management committee for the accuracy of travel claims which in turn were submitted to the MSC's CP agent. Care helpers occasionally undertook financial transactions for families. They were directly accountable to the families and the organiser for their recorded activities.

The scheme relied on public and private financial support and accounts were available for scrutiny by members of the public and by statutory bodies who had committee representation, at the Annual General Meeting.

#### Public Accountability (Political Issues)

Information about the service offered, to whom it was provided, and its future, became the subject of press coverage. The allocation of the service and its role within community care provision in Durham involved co-operation with other agencies and a responsibility to maintain the standard of care expected by the families, the public and other welfare agencies.

The need to ensure high standards had implications for selection and training of staff. The political issues within the organisation centred around who was ultimately responsible should a failure occur which adversely affected a family. Such a failure would become publicly known and have wide reaching affects on potential users, referees and funders. The issue of ultimate responsibility had

particular implications for the relationship between the committee and organiser. These problems are discussed fully in Chapter 3.

### User Accountability (Ideological Issues)

There is an obvious overlap between public and user accountability. Some users of the service were members of the management committee and public fund raisers. All users had access to statutory agencies and community representatives and hence were in a position to urge co-ordination of services (Gladstone 1979). Because of the origin of the scheme the management committee stressed their accountability to users. Ideologically the value placed on the rights of families to choose how to care for their members and make use of the support available in the way they wished demanded free communication and a management which accepted and acted on criticism. The committee would not use volunteer helpers primarily because of the lack of accountability (Abrams et al 1981, DHSS 1984). The sanction of discipline was rarely used against care helpers but it could be applied to reinforce standards of care, reliability and flexibility.

### FUNDING

The budgets agreed between the management committee and the MSC CP agent (The Boys Brigade Community Programme Agency) amounted to £45,000 for 1984/5 and £50,000 for 1985/6 (rounded figures, see Appendix 19 for details).

The determination of total funding and hours worked is based on an average wage worked out over the whole CP agency. Initially the wage

rates were £2.00 per hour for all the part-time staff. This was in line with local authority home helps and agreed with the GMBATU. During the course of the project the wage was raised to £2.33 an hour. There were also salary increases for the organiser and the senior care helper.

The allowance within the revenue figure made for travel costs was below requirements. Though increased in the second financial year the travel bill for care helpers and organiser had to be met in part by a one-off payment by the MSC via the CP agent towards revenue costs (6 months' rent) which freed resources in the first year.

Training was given a very high priority by the management committee. The budget allowance for training was inadequate, and the full cost was met only by using funds raised privately, relying on the good will of speakers and the generosity in terms of staff time of the health services and social services department for field work training.

#### Advantages of Funding Source

The advantages of MSC funding for any community project are the generosity of the total budget allocation and the speed with which the funds are made available. Both factors depend on the views of the agency which administers the resource and its preparedness to seek the best possible terms for its scheme. The Boys' Brigade CP agency showed initiative in backing a project which provided more than a sitting service. As a national CP agency it had well established links with trade unions, essential for the initial approval of the scheme, and the ability to average out wages nationally so that rates offered to care

helpers could be commensurate with home helps but still fall within the overall agency average of £60 per week.

#### Disadvantages of Funding Source

The disadvantage of MSC funds stemmed from the basic aim of reducing unemployment levels. The focus was on work experience for the employee and not the service they gave or the recipients of that service. This fundamental incompatibility proved unbridgable. Despite goodwill from the agency, their ultimate aim was identical with the MSC as their existence depended on a government grant. The prime problems were as follows:

- Employment of care helpers was for twelve months only.
- Applicants were restricted to those who have been registered unemployed for twelve months.
- Applicants had to be in receipt of state benefit (the restrictions, tightened half way through the first year, effectively excluded out-of-work women whose husbands' were working).
- Part-time work of 24 hours was expected to be carried out between 9 a.m. and 5 p.m. three days a week.
- There was no provision for enhanced rates of pay.
- Wages had to fall within an overall agency average of £60 per week.
- Employment of the maximum number of workers was expected as soon as funding was made available.



The scheme required:

- Employees able to adapt to needs of families (flexibility).
- Employees available when families required help. The restrictions of the funding meant rulings on hours which excluded from employment some of the most potentially flexible and reliable employees (people with no family commitment - often already in employment - who would be prepared to work anti-social hours).
- Employees who are easily contacted and have their own transport. Telephones and cars cannot be high priorities for those on state benefit.
- Permanent employees. Training is expensive and the need for annual training wasteful as well as disruptive for families.

### Efficiency

The limitations resulting from the funding choice inevitably reduced the efficiency of the scheme. Care helpers without cars could not work at times and locations not served by public transport. Their restricted mobility increased the time needed between visits and reduced the potential time spent caring.

The flat-week payment to care helpers for 24 hours a week made no allowance for anti-social hours which, as Appendices (15+16) show rose as high as 69% in June 1986. Although this avoided considerable extra costs to the scheme there was no provision for non-payment of hours not worked. Thus care helpers were paid a wage even when their call was cancelled. Over the first twelve weeks of 1985 an average of eighteen

hours a week were cancelled by families, approximately 15% of allocated calls.

A system of credit and debit hours was devised by management with the tacit agreement of the agent, but not of the MSC, to accommodate extra hours when demand was high. Excessive accumulation was avoided by care helpers having time off in lieu over a four week period. Interpreting the MSC rules very loosely it was possible to provide support on bank holidays, at night and on Christmas Day for example, when statutory services had no respite to offer carers at home.

A ratio of one organiser to one full-time care helper and nine part-time care helpers plus a clerical assistant working 30 hours per week, provided more administrative hours than were required. The clerical work could have been achieved in 20 hours a week but there were advantages to families and other agencies in having a permanently manned office.

### Cost Effectiveness

An assessment of the cost effectiveness of Durham Community Care was not the major concern of the evaluation. Comparable services did not exist in the immediate area and MSC resource allocations follow a standard formula for all CP schemes. The four-weekly totals of hours of work, including travel time, varied from 350 to 580. Such wide variations are explained by the small caseload in the first three months of the scheme until it became established, slight extra demand at certain times of the year, particularly the summer, and the need to support some disabled people with two care helpers, thus theoretically

doubling hours of care per family. Averaged over the two year period 150 hours of care per week were provided and this can be translated into an hourly cost for respite of roughly £7.50. This figure compares unfavourably with the estimated cost of Crossroads care of £4.00 per hour (average).

The costing of Crossroads schemes has been widely used to persuade joint funding bodies to support Crossroads Care Attendant Schemes. The management committee submitted an application for joint funds with guidance from the Crossroads Regional Development Officer (see Appendix ( 20 ) for budget). The estimated weekly hours of care required were based on a lower figure (130) than that provided by the scheme because of the duplication of some care by doubling up of care helpers and performance of care tasks more appropriately carried out by other agencies (see Chapter 5).

#### 'SAFEGUARDS AGAINST 'THE NEW''

Goldberg and Connelly (1982) argue the importance of evaluation as a safeguard against new fashions in forms of care, for example group living for elderly people, or patch-based social services delivery.

The importance of examining the current scheme lies in three factors. Firstly, the need to look closely at the effectiveness of the scheme in order to assess the general applicability of the service to carers in other areas.

Secondly, the resourcing of the scheme required careful scrutiny because of the policy implications for health and social services

departments. Health authority managers expressed an interest in the use of MSC funds for community schemes particularly in the light of community care proposals for long term hospital patients. When statutory services are under considerable financial pressure the offer to meet a gap through generous funding can be very tempting. The use of such money, however, can cramp creativity and responsiveness which should be the hallmark of consumer oriented activity.

Thirdly an important justification for evaluation of the scheme stems from the easy availability and lack of discrimination in uptake of MSC funds. The introduction of CP work schemes financed by the MSC had a considerable impact on the funding of voluntary activity. The voluntary sector supplied over half of the 255,000 places offered under CP schemes (Milne 1987). Money was readily available and voluntary organisations could move into an area setting up a project with little consultation with local service providers and no training arranged for participants.

At a local level 'care schemes' funded by MSC increased. Within a radius of 20 miles of the Durham Community Care area, four or five MSC funded schemes started over a two year period. These schemes, were however, sitting schemes or provided help with shopping, gardening etc. The lack of personal care to dependent people rendered them of limited use to carers. Nevertheless, their proliferation, under the same funding umbrella, invited comparison and, more seriously, confusion in the public mind and could have had deleterious effect on the reputation and likely referrals to Durham Community Care. It was important therefore, to provide an account of the service as a means of disassociation from other schemes.

### ROLE OF THE RESEARCHER

Abrams (1977) advocated action research evaluation as an appropriate method of researching small community care schemes. Close involvement does, however, create personal problems for the researcher. Problems of being within the system and outside at the same time, but with insight into the reality of the lives of the people who are the subject of the study. Proximity to the 'action' can cause 'role strain' (McGrath & Hadley 1981) and while objective judgements are sought their ellusiveness has, on occasions, to be accepted (Owens 1987).

Power and Kelly (1981) recognise also that researchers working in the community on some projects may have to take initiatives in starting services and giving support in the early stages. Such a view was taken in this study with considerable time being spent developing methods of data collection. When data were collected for more than one purpose the cooperation of the staff was essential and time was devoted to securing good relations and giving support to personnel.

### OUTCOME OF THE EVALUATION

The consumer response to the pilot project was clearly positive. While any critical 'measurement' of the effect of the scheme on carers was not possible, their views about the support they received and their fears about losing that help were unequivocal. Carers found the respite care offered met their individual needs and those of their dependants whom they could leave with complete confidence knowing they would be appropriately looked after by the care helpers. Many carers

expressed their appreciation in letters to the scheme's organiser, to its Chairman or to individual care helpers and also to the press. Some made donations of money to the Charity.

Nursing and social services agencies showed confidence in the scheme by referring families, despite uncertainties about continuity.

The views of all users were echoed by the Health Advisory Service/Social Service Inspectorate report on services for the elderly in Durham (1987) which pointed out the valuable role of the scheme in supporting carers and recommended that joint finance should be used to develop Durham Community Care as a Crossroads Care Attendant Scheme.

While the scheme did not achieve all its aims in full it highlighted the needs of carers for a flexible respite care service and demonstrated that it was possible to provide such a service.

The following, concluding chapter, considers the options open to respite care providers seeking to offer carers a flexible and responsive domiciliary care scheme.

CHAPTER 10CONCLUSIONINTRODUCTION

This investigation was carried out because, despite the rhetoric which accompanies any discussion of community care, families in Durham were caring for very disabled relatives and receiving very little support.

Within a short space of time families were identified who were caring for dependants needing constant supervision, a quarter of whom were unable to perform dressing/undressing, toileting, feeding or walking, unaided. They were people of all ages suffering from a range of disabilities; for example, multiple handicaps, degenerative diseases, stroke, cerebral palsy and Alzheimer's disease. About one in three carers was over 70 years of age. Carers were predominantly female and over half suffered excessive worry because of their caring responsibilities. Many reported poor health and feelings of isolation.

Despite the fact that the scheme operated with a fairly high press profile after nearly two years carers were identified through the door to door survey who were looking after very dependent people but had no knowledge of the respite service. This reinforces the need to seek out carers and make services known to them.

Although 'need' is a 'nebulous concept' (Owens 1987) the subjective view alongside objective measures must be given true weight. When carers express their needs they should be acknowledged as valid (Tinker 1981) and generate an appropriate response. Although difficult decisions may be required of policy makers (Caro 1981) when reacting to demand, in order to meet wide ranging needs, only carers are able to judge what they can and cannot tolerate and identify the services they require.

The vast majority of carers wish to continue to look after their dependant at home. Durham Community Care helped them and enabled them to keep in touch with the outside world.

The findings, therefore, support other investigations, which identify carers' needs and highlight the importance of respite care, but strongly suggests that domiciliary or home based respite care is more acceptable to carers than other forms of relief from caring.

The findings also support the contention that consumer opinion is important for formulating changes in social policy. It can only be effective, however, if an opportunity for choice allows consumers to express preferences and the predominant consumer voice is representative of the mass of individuals sharing the same problem. The survey findings suggest that carers' views had been realistically identified by the initiator and the process of evaluation produced information which eventually enabled change in local policy.



The unique value of the study lies in its examination of the tension between two unusual features of the scheme, its consumer initiation and orientation and its MSC funding.

This chapter considers means of providing the type of domiciliary respite service carers feel meets their needs and the implications for policy and further research.

### PROVIDING A RESPITE CARE SERVICE

MSC Community Programme funding is designed to provide work experience to the long term unemployed in activities which are beneficial to the wider community. Durham Community Care provided a service which was of benefit to the community but its success flowed from the vigilance of the committee and their manipulation of the Community Programme rules to ensure a responsible service. A secure source of funding became crucial for the families.

Suitable staff were essential. Care helpers were required to show warmth and acceptance, flexibility, honesty and resourcefulness. Staff had to be capable of discrimination and responsiveness in highly stressful relationships (Owens 1987). It was necessary to wait for the right people and it would have been preferable to have been able to reward them with adequate pay and recognition (Owens 1987). Care staff are categorised as manual workers, reflecting the status given to such work (Finch and Groves 1980). Those working in the community (and institutions) require emotional support as well as better financial rewards (Rowlings 1981) to fairly reflect the responsibilities they assume. Neither could be adequately provided under MSC funding.

## POLICY IMPLICATIONS

Policy makers show ambivalence about the nature and support to be offered to carers. It has been suggested that better integrated and improved services could increase families' expectations of help and lead to a withdrawal of informal carers (Land 1978, Hadley 1981), or carers may withdraw when alternative support is forthcoming to become re-involved when the burden of care is shared (Wenger 1984).

This study shows that the majority of carers have no wish to withdraw and were enabled to continue because of the relief gained through shared care.

The opportunity for domiciliary respite care should be available to every caring family as part of a package of care. As MSC funding for domiciliary respite is unsatisfactory the issue revolves around the relative benefits of secure funds administered by the statutory or voluntary sector.

A new service has to establish credibility, particularly when it tries to attract clients in the early stages of requiring help (Blaxter 1976). The operational umbrella, therefore, is of more than financial significance. Joint finance is available for community care developments in preference to institutional care. Such developments should start with the needs of the patient/client rather than the administrative and professional interest of the service (Richard 1980, Sainsbury 1982).

The role of carers necessarily transcends professional boundaries. They may perform 'nursing' tasks in a 'social' context and there is a danger of causing inflexibility in a service by pigeon-holing the relief care in a health or social services model (Owens 1987). The voluntary sector can avoid inflexibility and offer a responsible respite care service. The skills of nursing and social services personnel should be used more effectively to inform and guide families and to train and support care helpers/attendants who require a range of knowledge and skill to cope with nursing and social needs.

The advantages of the voluntary sector lie in its adaptability, cost effectiveness, greater participation of recipients of services and the wider community. It has the potential to perform a co-ordinating role, linking welfare services, statutory and voluntary for the benefit of individuals (Gladstone 1979). It is in a better position than statutory services to experiment and test out care options (Johnson 1981) provided services remain client oriented and responsive and do not adopt an altruistic philosophy (Borsay 1986).

The Audit Commission concluded that the voluntary sector can make a major contribution to caring for carers by providing through a Crossroads Scheme\*, the kind of help families required.

"This conclusion was reinforced by the judgement that a care attendant scheme would have to be re-invented if Crossroads lapsed.

---

\*Review of the Essex Crossroad Care Attendant Schemes.

Given a positive message of support, coupled with regular short periods of relief and confidence in the care attendants, the majority of disabled people and carers alike see Crossroads as a long-term alternative to residential care."

(Audit Commission 1986)

The logical development of the Durham service lay within the voluntary sector as a Crossroads Scheme. The following factors influenced this view:

- a shared philosophy of care which recognised the needs of carers of the physically handicapped
- a service free at the point of delivery
- a 'family substitute' approach to the job description of care attendants which did not restrict their caring activities
- the autonomy of each scheme
- the prerequisite of permanent funds for a scheme, thus ensuring continuity of care and employment of care staff.

Griffiths (1988) recommends that responsibility for care in the community should lie with social services departments who should become 'arrangers and purchasers, not monopoly providers' of community care services. Provided resources are available, 'buying in' domiciliary respite in the form of Crossroads Care Attendant Schemes seems a good way of providing support to carers.

POSTSCRIPT

Durham Community Care operated for a third year financed by further MSC funds. There were changes in care staff and a new organiser but the voluntary management committee remained substantially unaltered.

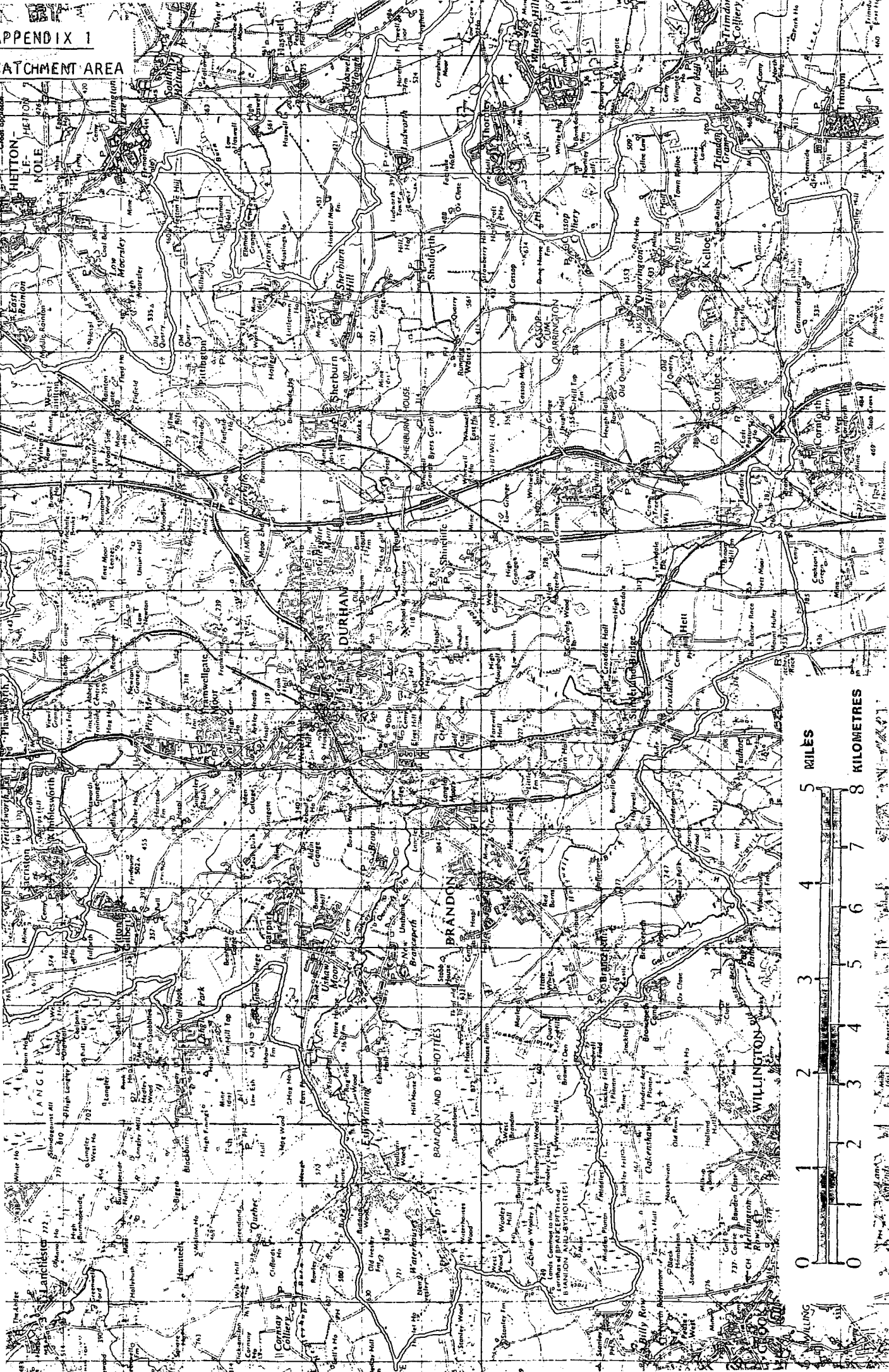
A management decision had been made in 1985/86 to form a Crossroads Steering Committee which comprised the existing Durham Community Care committee and other interested individuals. The committee achieved the goal of joint funding after intensive marketing of the proposal for a Crossroad Scheme and lobbying for its acceptance.

The inauguration of Durham District Crossroads Care Attendant Scheme took place on the 23rd June 1987 and the scheme began operating on 1st July that year, just twelve months after the end of the research period.

Appendices

1. Map of the Catchment Area of Durham Community Care
2. Newspaper Notice
3. Survey of Families: Interview Schedule; Level of dependency
4. Survey of Families: Interview Schedules; Care given
5. Survey of Families Coding Sheet
6. Survey of Families: Interview Manual
7. Ex-carers Survey: Letter to previous users of Durham Community Care
8. Ex-carers Survey: Postal Survey Questionnaire
9. Door to Door Survey; Leaflet
10. Door to Door Survey; Interview Schedule
11. Weekly Task Survey: Care Helper Task Schedule
12. Weekly Task Survey: Organiser's Information Sheet
13. Care Helpers' Survey: Letter
14. Care Helpers' Questionnaire
15. Hours of Respite Care Provided by Durham Community Care in 2nd Year of Study
16. Hours of Respite Provided to Families Throughout Two Years
17. Induction Training Course for Care Helpers
18. Care Helper Diary
19. Budget of Durham Community Care
20. Provisional Budget for Durham Crossroads Care Attendant Scheme

ATTACHMENT AREA



APPENDIX 2CARING FOR CARERS SURVEY OF FAMILIES PILOT SURVEYInitial Advertisement

Newton Hall Parish Magazine - March 1984

Durham and Chester-le-Street Trader - April 3rd 1984, April 10th 1984

A group of individuals in Durham are looking into the support which is given to people who are looking after the severely handicapped and frail, of any age, who are living at home. If you live in the Durham City area and have anyone for whom you have to care, on a daily basis and who is dependent on you, would you be prepared to be visited by one of the group to talk confidentially about your situation? If so, please telephone Durham 64239 or Durham 61833 and leave your name.



APPENDIX 3

SURVEY OF FAMILIES

INTERVIEW SCHEDULE

LEVEL OF DEPENDENCY

INTERVIEW SCHEDULE SURVEY OF FAMILIES

LEVEL OF DEPENDENCY

Interview date .....

1. Name: Age: Sex:

Address:

Disability:

2. Main Carer:

A. Domestic abilities

3. Does person have difficulty with following?

a. Shopping

b. Washing clothes

c. General housework

d. Preparing hot drink

e. Preparing hot meal

CODE

- 1 - no difficulty
- 2 - only with difficulty
- 3 - cannot do

Has person carried out above tasks in the past? YES NO (ring)

B. Mobility

4. Is person able to get about?

a. Walking unaided

b. Walking with help from another person or persons

c. Walking with an aid (stick, zimmer, brace)

CODE

- 1 - no difficulty
- 2 - only with difficulty
- 3 - cannot do

Mobility dependent on assistance - (tick and comment if appropriate)

a. Wheelchair self propelled

b. Wheelchair - only if pushed

c. Car - if driven

d. Chair bound

CODE


CODE


5. Is person able to climb flight of stairs (if necessary)?

CODE


a. Unaided

b. If helped by one person

c. If helped by more than one person

d. Has chair lift

CODE

1 - no difficulty

2 - only with difficulty

3 - cannot do

6. Does the person fall?      YES      NO      (ring)  
If 'yes' when did he/she fall?

C. Personal Care

7. Does person have difficulty with the following?

CODE


a. Feeding him/herself

b. Dressing/Undressing

c. Doing up buttons and zips

d. Putting on shoes and socks/  
stockings

e. Getting in and out of bed on own

f. Getting in and out of chair

CODE

1 - no difficulty

2 - only with difficulty

3 - cannot do

8. Does person have difficulty with the following?

CODE


a. Getting to or using W.C.

b. Having all-over wash or bathing

c. Washing hands and face

d. Combing and brushing hair  
(men/shaving)CODE

1 - no difficulty

2 - only with difficulty

3 - cannot do

9. Is person incontinent of urine?

CODE


- a. At night
  - b. During the day
- Can person be kept dry  
if washed?

CODE

- 1 - never
  - 2 - occasionally
  - 3 - more than once  
a week
- N/A YES NO (ring)

10. Is person incontinent of faeces?

CODE


- a. At night
  - b. During the day
- Can person be kept clean if  
manual evacuation given?

CODE

- 1 - never
  - 2 - occasionally
  - 3 - more than once  
a week
- N/A YES NO (ring)

(Nos. 11-15 elaborate if required)

D. Cognition and Communication

11. Is person confused?

RING

a. Not at all	1
b. Mildly	2
c. Severely	3
d. Very severely	4

12. 'Mental state'

RING

a. Good, stable	1
b. Occasionally 'down'	2
c. Slightly anxious, depressed	3
d. Moderately anxious, depressed	4
e. Very anxious, depressed	5

13. Articulation

a. Clear, meaningful speech	1
b. Speech occasionally unclear	2
c. Speech meaningful, strangers cannot understand it	3
d. Speech meaningful, family cannot always understand it	4
e. Little or no meaningful speech	5

14. Vision

a. Normal	1
b. Normal with glasses	2
c. Partially sighted (registered YES NO D/K	3
d. Blind (registered YES NO D/K	4

15. Hearing

a. Normal	1
b. Mild deafness	2
c. Moderate deafness	3
d. Severe deafness	4
e. Hearing aid	5
f. Lip reads	6
g. Sign language	7

16. What aids are in use?

TICK	TICK
Electric Wheelchair	Artificial limbs
Wheelchair	Incontinence pads
Zimmer	Hearing aid
Calipers	Telephone
Sticks	Commode
Hoist	Other (specify)

17. Has home been altered in any way?

Extension, downstairs toilet etc. (please specify)

APPENDIX 4

SURVEY OF FAMILIES  
INTERVIEW SCHEDULE  
CARE GIVEN

APPENDIX 4INTERVIEW SCHEDULE: SURVEY OF FAMILIESCARE GIVEN

Interview date .....

1. Dependant:

Name:

Age:

Sex:

Address:

Disability:

2. Main Helper:

Age:

Sex:

Relationship:3. Help given to dependant by main carera) Times of help given (tick)

Weekdays 9 - 5

Evenings 5 - 12 midnight

Weekends 9 - 5

Nights 12 midnight - 9 am

b) Frequency of help give (tick)Personal care once every 3 hours  
2 hours  
1 houronce every half hour  
continuous observation4. Support for Main Carer

a) What physical help with dependant is received from friends, neighbours, other family? (specify)

b) Does main carer have emotional support from friends, neighbours, other family? (specify)

5. Professional Support

a) What professional help is received (specify)

b) Has any professional help been refused? Yes No  
(if 'Yes' please specify help offered and reasons for refusal)



6. Other Support

- a) How often are other social contacts seen i.e. those not seen as main helpers? (Specify contacts and nature of visits)

## DETAILS

Daily

2-3 times a week

within last week

within last month

within last 3 months

Once a year

7. Invite comment on the quality of relationships with lay people involved. Specify family, friends, voluntary agencies.
8. How could these relationships provide more help to carer?
9. Interviewer's comments on description of support available.

10. Care Matrix: Main Carer

How long has person been main carer?

If less than 2 years what was the main carer's former relationship with and responsibility for the dependant?

Use code for A - P below to complete matrix on scale 1-5  
(1 = good, 5 = bad)

	1	2	3	4	5	N/A 6
A. Physical health	A					
B. Tiredness	B					
C. Loss of sleep	C					
D. Age	D					
E. Emotional state	E					
F. Coping with physical care	F					
G. Extra work for helper	G					
H. Outside employment	H					
I. Isolation	I					
J. Physical/emotional support from friends/relatives	J					
K. Financial situation	K					
L. Financial sources	L					
M. Responsibility for others	M					
N. Relationship with dependent	N					
O. Relationship with other family members	O					
P. Relationship with statutory/ professional carers	P					

APPENDIX 5INTERVIEW SCHEDULE CODING SHEETSURVEY OF FAMILIES CARE GIVEN

Coding Sheet to be used when completing Q. 10. Care Matrix (Appendix 3)

Physical health

- A. Very fit. 2. No health problems. 3. Minor health problems. 4. Major health problems. 5. Too ill to care for dependant or died.
- B. Tiredness  
 1. No tiredness. 2. Unusually tired at night time. 3. Tired all day. 4. Very tired. 5. Too tired to manage basic care.
- C. Loss of sleep  
 1. No loss of sleep. 2. Occasional loss of sleep. 3. Sleep unbroken but total reduced. 4. Sleep usually broken once each night. 5. Sleep broken several times each night and reduced.
- D. Age in years  
 1. Up to 19 2. 20- 39 3. 40 - 59 4. 60 - 69 5. 70+.
- E. Emotional State (self definition)  
 1. Copes well with extra pressure. 2. Copes well but often irritable. 3. Occasional "down". 4. Anxious/depressed/irritable. 5. Very anxious/depressed/irritable.
- F. Coping with physical care of dependant  
 1. Copes easily. 2. Copes with some difficulty. 3. Copes with extreme difficulty. 4. Cannot cope alone - manages with outside help. 5. Cannot cope alone - outside help insufficient.
- G. Extra work for helper  
 1. Minimal responsibility for housework. 2. Usual housework role. 3. Housework role slightly more than usual. 4. Housework role considerably more than usual. 5. Full time outside work plus all housework.
- H. Outside employment  
 1. Helper forced to retire. 2. Helper prepared to retire if necessary. 3. Helper able to modify job to accommodate caring responsibilities. 4. Change would help but is unlikely. 5. Helper will not change job at all.

I. Isolation

1. Helper lives normal social life. 2. Minor constraints on social life. 3. Social life reduced. 4. Able to go out for short periods only. 5. Helper rarely leaves house.

J. Physical/emotional support from friends/relatives

1. Reliable support from several locals. 2. Reliable support from 1 local. 3. Reliable support from non-local source. 4. Occasional visits from relatives and friends. 5. Little or no support.

K. Financial situation

1. Manages well/comfortably. 2. No money problems. 3. Minor money problems. 4. Serious problems but manages. 5. Hardship.

L. Financial sources

1. Main carer's salary/wage. 2. Wage plus benefits. 3. State benefits. 4. State benefit and allowances including gifts. 5. Are all entitlements being received?.

M. Responsibility for others

1. None. 2. Minor responsibility for others outside household. 3. Responsible for other adults. 4. Considerable responsibility e.g. children, elderly relatives. 5. Helper burdened by responsibility for others.

N. Relationship with dependant

1. Very good. 2. Reasonably good. 3. Resentful and argumentative at times. 4. Poor all the time. 5. Bad - resulting in neglect/violence.

O. Relationship with other family members

1. Very good. 2. Good most of the time. 3. Poor, frequent quarrels. 4. Family members move away because of poor relationship. 5. Always lived alone.

P. Relationship with statutory/professional carers

1. Very good - receiving a lot of support. 2. Regular contact. 3. Infrequent contact. 4. Known to agency but no assistance given. 5. Not known to any agency.

APPENDIX 6INTERVIEWER GUIDELINES SURVEY OF FAMILIES

Interview Manual to be used with Interview Schedules - Survey of Families

Level of Dependency and Care Given (Appendices 3 & 4)

Dependence Level

- A.3 If person has never carried out domestic tasks but has been physically capable of doing so, state reasons for not carrying out such tasks.
- B.5 d. If no chair lift mark box thus X.  
If chair lift is used, use code to indicate if it can be used by person unaided.
- C. 7a-f If person can manage tasks very slowly, but unaided use code 2. If help is required use code 3.  
b. If person can dress but not undress, underline dressing and complete box and put code No. 3 against Undressing:  
c. Follow procedure as for b. by underlining task assessed in box and putting number by second task.
- C. 8a-d If person needs help with these tasks use code 3.  
a. If person has difficulty getting to toilet but not using it underline "getting to" and code accordingly and put code number next to "using W.C."  
b. If person can bathe himself unaided but cannot get in and out of the bath without help use code 2 against word "bathing". Underline "all over wash" and code in box if different from bathing.

Care Level

3. a. Times of help given means - during what period of the day does the dependant require help?  
Help means any practical assistance whether personal care, general care or supervision to prevent accidents.
4. a. "Physical help" means assistance with personal tasks for dependant and or preparing food or doing laundry etc. specifically for dependant.  
b. "Emotional support" to include friends, neighbours etc. running errands but specify this type of help. Indicate separately help in form of sharing anxieties.
5. a. Include here periods of intermittent care or day care, school or clubs which relieve carer of responsibilities for part of the day.
6. a. Other support to include all contacts not referred to in 4 and 5.
- 7 + 8 Interviewee's assessment of relationships and possible improvement. Interviewer to interpret this if necessary below 'comments'.

# Durham Community Care

44 OLD ELVET  
DURHAM  
DH1 3HN  
Tel: (0385) 69513

Dear

As a member of the Management Committee of Durham Community Care I am conducting a survey of the families who have had contact with this service in the past. This is part of my research into the stresses carers suffer, and the effect, if any, a respite care scheme can have in reducing those stresses.

I know that I am imposing on you by asking you to consider completing the enclosed questionnaire and perhaps re-live painful experiences. Your co-operation, however, would be very much appreciated because the better the general understanding of caring and the more carefully a scheme is monitored, the better the support service that can be offered.

I must assure you that everything you write will be treated completely confidentially.

I have enclosed a stamped addressed envelope for your reply and would like to thank you most sincerely for your assistance. If you would like to add anything to the questionnaire, please feel free to do so and if you think I am able to help in any way, do contact me at my home.

Yours sincerely

Monica Smith  
Researcher and Treasurer  
Durham Community Care  
Management Committee

Home Address

28 The Avenue  
DURHAM CITY  
DH1 4ED  
Tel: 64239

APPENDIX 8

EX-CARERS SURVEY  
POSTAL QUESTIONNAIRE

EX-CARERS SURVEYPOSTAL QUESTIONNAIRE

Please answer the questions as fully as possible. If there is insufficient space use the back of the sheet.

Name of Carer:

Name of Dependant:

1. What was the matter with the person you cared for?  
(your dependant).  
.....
2. How long in total did you care for dependant?  
.....
3. For how long in every 24 hours could your dependant be safely left alone?  
.....
4. Whilst caring for your dependant relative who else (if anyone) did you have responsibility for in your household? (Please explain)
5. What help (if any) did you receive from relatives/friends?  
(Please explain who your helpers were, what help they gave and how frequently they called.)
6. What help did you get from the "authorities"?  
(e.g. Meals on Wheels, District nurse, Church etc.)



7. Was your life restricted in any way by Caring?

8. If your answer to question 6 is "yes" could you please explain briefly how your life was affected in any, or all of the following ways.

TIREDFNESS

PHYSICAL STRAIN (e.g. injury from caring tasks etc.)

EMOTIONAL STRAIN (e.g. depression, resentment, loneliness etc.)

RESTRICTED WORKING LIFE (e.g. needing to change jobs, retired early etc.)

RESTRICTED SOCIAL LIFE (e.g. unable to go out, lost touch with friends etc.)

IN ANY OTHER WAY NOT MENTIONED ABOVE

9. What is your health like compared with people of your own age?

Good	<input type="checkbox"/>
Moderate	<input type="checkbox"/>
Poor	<input type="checkbox"/>
Variable	<input type="checkbox"/>

10. What were your reasons for caring for your dependant at home?

11. What benefits, if any, did you gain from the visits Durham Community Care Care-helpers made to you?

12. Any other comments. Please use the back of this page if there is anything more you would like to express about your experience as a carer.

APPENDIX 9CARING FOR CARERSDOOR TO DOOR SURVEY LEAFLETDOES SOMEONE NEED YOUR HELP EVERYDAY?

A group of individuals in Durham are looking into the support which is provided for people caring for those who are handicapped and frail and living in their own homes. If you have responsibility for the daily care of someone who is dependent on you, would you be prepared to discuss your situation, confidentially, with a member of the group?

Someone will call again within the next few weeks but if, in the meantime, you would like to get in touch to arrange an appointment, please telephone Monica Smith on Durham 64239 after 4. p.m. or leave a message on Durham 61833 or Durham 64466 extension 259.

APPENDIX 10

CARING FOR CARERS

DOOR TO DOOR SURVEY

Interview Schedule

DOOR TO DOOR SURVEY OF CARERS AND CARING

I am conducting a survey about the people who look after members of their family, or friends, who are unable to look after themselves. Would you mind if I ask you a few questions?

There is no right or wrong answer to anything, and everything you tell me will be treated confidentially.

Number:

Interview date:

Tick

Yes No

1. Do you have anybody who is handicapped, chronically sick or frail who is dependent on you, every day, for help with their personal care?

--	--

2. Have you ever had the responsibility of caring for someone who was dependent on you every day for their personal care?

--	--

If NO to 1 and / or 2:

3. Please could you tell me who lives in this household, their ages and who is working?

ADULTS					CHILDREN			
Male	Age	Female	Age	Employment	Male	Age	Female	Age

If YES to 1 and / or 2:

4. What is (was) your relationship to the person you cared for?

.....

5. What is (or was) the name of:

(a) the person you care (cared) for? .....

(b) and his/her age? .....

6. Does (did) your ..... (dependant) live with you?

Yes ..... No .....

If NO how far does he/she live? .....

7. How long have (did) your care(d) for him/her? .....

8. What is (was) the matter with your ..... (dependant)?

9. What help do (did) you have to give your ..... (dependant)?

Please describe what you do (did) for your relatives:

Does (did) he/she need help	2-3 times a day	<input type="checkbox"/>
or	every hour in the day time	<input type="checkbox"/>
or	continuously day and night	<input type="checkbox"/>
or	other	<input type="checkbox"/>

10. When did you last have a break from your relative? .....

What is your health like compared with people of your own age?

Would you describe it as:

Good

Moderate

Poor

Variable

11. Please can you explain to me why you care(d) for your ..... dependant?

12. Do (did) you have other responsibilities apart from caring?

Yes

No

for your ..... dependant?

Please explain:

(Probe) e.g. In and Outside the home.

13. Does (did) caring for your dependant affect your life?

Yes

No

(Probe) Has it affected your family, social or work life?

Has it affected you financially?

Yes

No

(Probe) Please explain.

14. What practical help do (did) you get from:

Relatives?

Friends/Neighbours?

The Authorities? (Specify) (Probe) church, voluntary groups.

15. How do you think your situation could be improved?

16. Could you please give me:

(a) Your name? .....

(b) and your age? .....

(c) and your occupation? .....

Thank you very much for your help. The information you have given me with be treated confidentially.



WEEKLY TASK SURVEYCARE HELPERS' TASK SCHEDULE Year .....Survey of tasks undertaken by Care Helpers week beginning:

(One form to be completed by Researcher for each family, in presence of Care Helper).

Care Helper:

Interview date:

Name of Dependant

Does dependant live alone?

Address of DependantAge:Sex:Disability:Main Carer:Relationship:Age:

## 1. Pattern of visits by Care Helper

DATE	DAY	FROM:	TO:
	Fri		
	Sat		
	Sun		
	Mon		
	Tues		
	Wed		
	Thurs		

2. Was this a typical week in terms of number of visits and their length?

Yes

No

If NO explain.

HOUSEHOLD CARE

	<u>YES</u>	<u>NO</u>	<u>CODE</u>
3. Cleaning - a. house cleaning			1
b. bed making/changing			2
c. washing up			3
d. washing floor			4
e. other (specify)			5
4. Shopping - a. essential food			6
b. paid bills			7
c. collected pension/ prescription			8
d. escorted dependant shopping			9
5. Meal Preparation - a. prepared full meal			10
b. made hot drinks			11
c. fed person (meal)			12
d. fed person (drinks)			13
e. ate a meal with person/ or drink			14
f. prepared food to be eaten later			15
6. Fire/ heating - a. cleaned grate/and relit			16
b. fetched fuel/stocked fire			17
c. adjusted central heating			18

7. Laundry	- a. washing:			19
	1. personal 2. household			
	b. ironing:			20
	1. personal 2. household			
	c. dealt with incontinence laundry			21

If yes to c. what did care helper do with laundry?

8. <u>PERSONAL CARE</u>	a. helped person get up/ dressed			22
	b. helped person undress/ go to bed			23
	c. helped person wash			24
	d. helped person to shave/ do their hair			25
	e. helped person bath/shower			26
	f. gave blanket bath			27
	g. washed person's hair			28
	h. helped to cut nails (toe or finger)			29
	i. helped person to toilet (or commode in same room)			30
	j. emptied commode			31
	k. dealt with other incontinence equipment			32
	l. cleaned up after "accident"			33
	m. helped or supervised person move around house (up or down stairs)			34
	n. walked person as therapy			35
	o. massaged (stiff joints etc.)			36
	p. turned/lifted chair/ bed bound person			37
	q. cared for pressure sores			38
	r. supervised taking of medicines			39
	s. cleaned teeth			40
	t. other personal tasks (e.g. manual evacuation)			41

9. GENERAL CARE/SUPPORT

- a. sorted clothing
- b. helped write letters
- c. read to person
- d. fed pets
- e. sat and chatted
- f. did sewing/mending
- g. other incl. watching TV

		42
		43
		44
		45
		46
		47
		48

10. SUPPORT OUTSIDE NORMAL DUTIES

- a. stayed longer than scheduled visit
- b. popped in when passing
- c. went to library/shops etc. in own time
- d. other (specify)

YES NO CODE

		49
		50
		51
		52

11. Where was main Carer during your visit?

- a. in the house
- b. out shopping/appointments  
(underline)
- c. at work
- d. other (specify)

		53
		54
		55
		56

- 12. a) Was this a typical week in terms of use of your time with this person?
- b. If you are not the regular Care Helper was the use of your time typical as far as you know?

13. As far as you know did this person receive practical help from any of the following sources this week?

Indicate number of visits from each. If visits were Social mark (s)

	YES	NO	D/KNOW
Neighbour)			
Friend ) Other than Main Carer			
Relative			
District nurse			
Health visitor			
Home help			
Meals on wheels			
Voluntary visitor			
G.P.			
Other			

14. As far as you know has he/she visited any of the following this week? \*

Lunch club			
Day centre			
Hospital			
Other			

\*Indicate how many times.

15. Have you discussed this person with your supervisor since your visit this week?
16. Has anything occurred during this week to give you anxiety about this person?

Thank you for your help.

WEEKLY TASK SURVEY  
ORGANISER'S INFORMATION SHEET

Year .....

Survey of tasks undertaken by Care Helpers week beginning:

To be completed by the Organiser: (one form for each dependant person)

Survey of tasks Organiser expects Care Helpers to perform when allocating work

1. Name, address of dependent person:

2. Age: Sex:

3. Name of main carer:

Age: Sex:

5. Number of hours help allocated by organiser:

6. Number of hours help usually provided:

7. Number of Care helpers involved. Names:

8. Days on which help was received (ring):

---

Mon. am	Tues. am	Wed. am	Thurs. am	Fri. am	Sat. am	Sun. am
pm	pm	pm	pm	pm	pm	pm
even	even	even	even	even	even	even
n't	n't	n't	n't	n't	n't	n't

---

9. Reason for dependence ‡ (underline as appropriate on 4)

1. Physical disability

2. Mental disability

3. Multi-disability

4. Temporary dependence, discharge from hosp/  
broken limb etc.

	1
	2
	3
	4

10. Categories of support to be given: (underline as appropriate on 3,5 and 6)

1. Cleaning
2. Shopping
3. a) Meal preparation    b) Drink preparation
4. Feeding
5. Fire/heating
6. Laundry    a) household    b) personal
7. Personal care
8. General care
9. Other

	1
	2
	3
	4
	5
	6
	7
	8
	9

11. Has any form of institutional care been considered or offered to this person to your knowledge?

If Yes give details.

12. Would this family benefit from more help from D.C.C.?

If yes reasons for not providing more help.

- tick    a) insufficient resources  
           b) family will not accept more

13. Organiser's Priority ranking:    P1  
                                                   P2

44 OLD ELVET  
DURHAM  
DH1 3HN  
Tel: (0385) 69513

Dear

May I please impose on you and ask you to fill in this questionnaire. I know that I covered much of this with you at the start of your working period with Durham Community Care but would like to use the same formula for you and the present Care Helpers.

As you may know we are still struggling for permanent funding and are faced with the third changeover this summer. The research angle continues to be an important side of the argument for secure funds and the training programme has to be evaluated.

Please help!

I hope you are well and enjoying whatever activities you are now engaged in.

Best wishes,

Monica Smith



DURHAM COMMUNITY CARETRAINING PROGRAMMEQuestionnaire for completion by past and present Care Helpers1. NAME Date Completed2. PREVIOUS EXPERIENCE

2a. Please give details of any post-school qualifications.

Dates	Qualifications	Completed	Not Completed

2b. Please give details of work experience prior to working for Durham Community Care.

2c. Did any of your work experience include in-service training?

Please tick

Yes	No
-----	----

If Yes please give details:

- 2d. Did you have any relevant family or voluntary experience before starting work as a Care Helper?

Please tick

Yes	No
-----	----

If Yes please give details:

### TRAINING

On attached sheets (p. 5 & 6) please tick the aspects covered in your induction and in-service training

### 3. INDUCTION TRAINING

- 3a. Do you think your Durham Community Care induction prepared you adequately for your work as a Care Helper?

Please tick

Yes	No
-----	----

- 3b. What aspect was most useful?

- 3c. What aspect was least useful?

- 3d. Would you have liked more guidance on any particular aspects.

Please tick

Yes	No
-----	----

- 3e. If Yes: Please state what these aspects were.

4. IN-SERVICE TRAINING

4a. Did you find any of the in-service training programme useful?

Please tick

Yes	No
-----	----

4b. What aspects did you find useful?

4c. What additional aspects would you have liked included?

4d. What aspects, if any would you have

i) liked to cover more

ii) liked cover less.

5. Please give your comments on the supervision you received from the organiser?

6. Please give your comments on the allocation meetings on Fridays?

7. Are there any other aspect of training on which you would like to comment?

## 8. PAST CARE HELPERS

8a. Are you working at the present time?

Please tick

Yes	No
-----	----

8b. If yes: What is your present job?

8c. Does your experience as a care helper help you with your present work?

Please tick

Yes	No
-----	----

Please elaborate.

8d. If funding of Durham Community Care had been secure would you have wished to continue working as a care helper?

Please tick

Yes	No
-----	----

Thank you for spending time completing this questionnaire.  
Your help is appreciated.

NAME:

INDUCTION COURSE

	Please tick if you participated
<b>1. INTRODUCTION</b>	
1. Lecture on background and philosophy of scheme	
2. Introduction to work and office procedure	
3. Conditions of employment, health and safety.	
<b>2. LECTURES AND DISCUSSIONS</b>	
1. The role of the District Nurse	
2. The role of the Social Services Department	
3. The role of the Community Psychiatric Nurse	
4. Caring for the mentally/physically disabled at home	
5. Nursing in the home	
6. Disabilities, medical diagnoses and care	
7. Lifting techniques	
8. Bereavement	
9. Psycho-sexual problems. The handicapped and the Carer.	
<b>3. DAY COURSES</b>	
1. The meaning of disability (Workshop)	
2. First aid training course: Red Cross Boys Brigade	
3. Lifting and posture seminar	
<b>4. PLACEMENTS</b>	
1. 3-5 days Home visiting with District Nurse	
2. Hylton House. 1 day.	

5. VISITS

- 1. Multiple Sclerosis Society Group Meeting
- 2. Aykley Day Centre
- 3. Earls House Hospital
- 4. Aykley Heads School

6. HOME CARE

Training with families caring for severely disabled relatives. Brady's/Coates'.

7. ESCORTED VISITS

With Organiser and/or in-post Care Helpers to supported families.


IN-SERVICE TRAINING

- 1. GROUP ACTIVITY
  - 1. Sign Language for deaf
  - 2. Practice sessions on lifting techniques
- 2. TALKS
  - 3. Listening techniques
  - 4. Trade Unions
  - 5. Durham Home Care Relief Group
- 3. VISITS
  - 6. Mea House/Dene Centre Newcastle
  - 7. Project work


Thank you for completing this part of the questionnaire.

APPENDIX 15

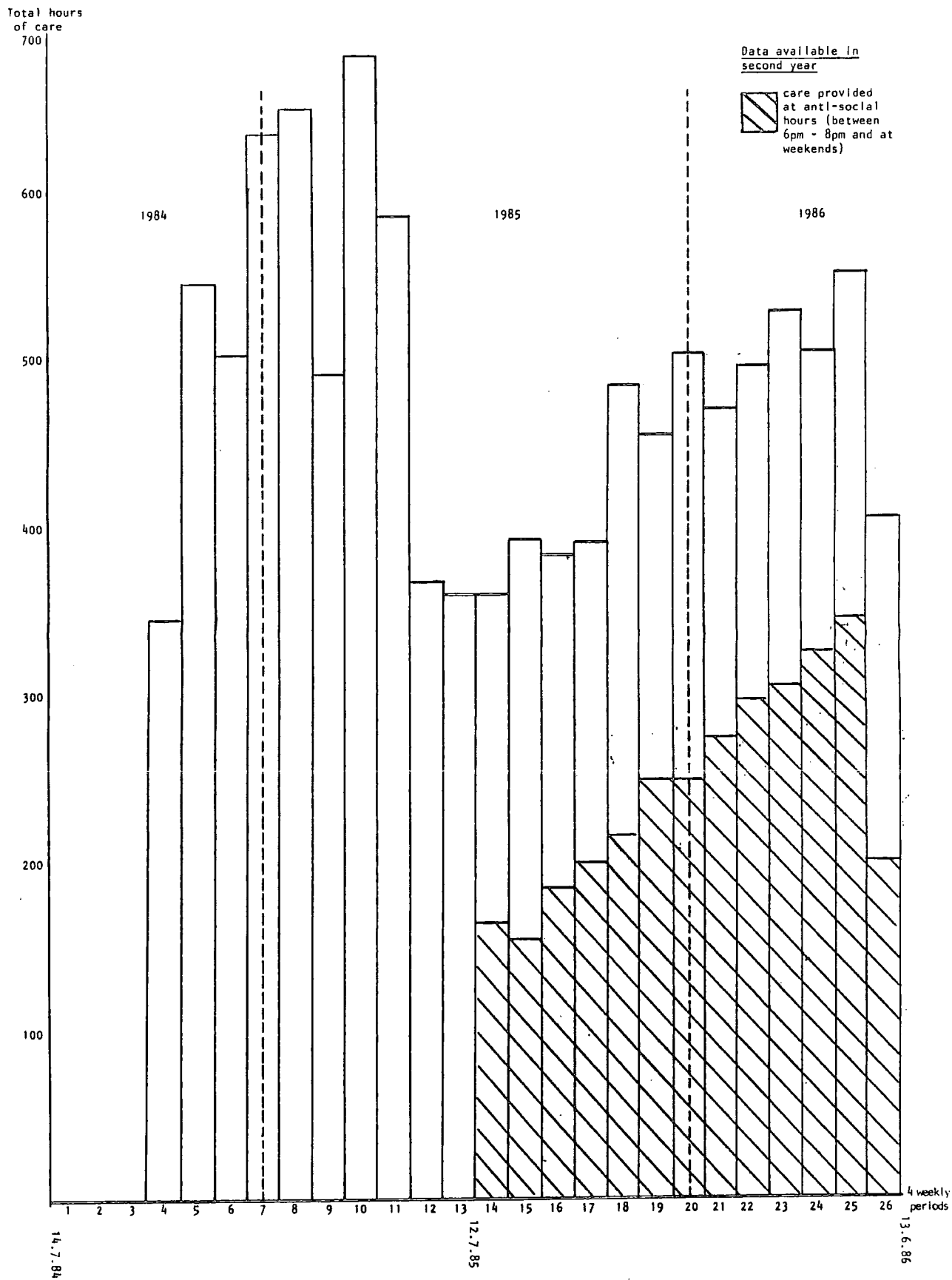
HOURS OF RESPITE CARE PROVIDED BY  
DURHAM COMMUNITY CARE IN SECOND YEAR OF STUDY

12.7.85 - 13.6.86

4 weekly period		Total hours of care provided	Total hours at weekends and nights	% of care hours at anti-social times	Caseload
		No.	No.	%	No.
No.	w/ending				
14	12.7.85	351	160	46	59
15	9.8.85	379	152	40	53
16	6.9.85	382	194	51	52
17	4.10.85	472	210	45	45
18	1.11.85	438	245	56	47
19	29.11.85	494	266	55	58
20	27.12.85	480	266	55	58
21	24.1.86	467	284	61	55
22	21.2.86	472	317	67	61
23	21.3.86	531	335	63	70
24	18.4.86	482	334	69	59
25	16.5.86	581	368	63	63
26	13.6.86	398	277	69	65

APPENDIX 16

HOURS OF RESPITE CARE PROVIDED TO FAMILIES THROUGHOUT TWO YEARS  
 (Data unavailable until 6.10.84)





APPENDIX 17INDUCTION TRAINING COURSE FOR CARE HELPERS

1. Introductory talks: Background and philosophy of scheme.  
Tricia Brady/Monica Smith
2. Conditions of Service.  
Mr Heevisides - Boys Brigade C.P. Agency
3. Day to day organisation.  
Ros Layton
4. Lectures: Role of the district nurse.  
Sister Sowerby
5. Nursing in the home.  
Sister Thompson
6. State Benefits and Allowances.  
Maggie Weekly, CAB
7. Disabilities, their causes and effects.  
Dr Holmes/Dr Kneer
8. Caring for mentally/physically disabled  
at home.  
Mrs Sheila Jones
9. (Physiotherapist) Lifting techniques.  
Mrs Sneddon
10. Bereavement.  
Jenny Hockey, CRUSE
11. The role of the Social Services department.  
Carol Sommerville
12. Psycho-sexual problems. The handicapped and  
the carer.  
Dr Munro
13. The role of Community Psychiatric Nurses.  
Don Kent and Bob Ord
14. Day Courses: Normalisation Workshop.  
Ken and Sue Smith
15. First Aid Training.  
Red Cross
16. Placements: Home visits with District Nurses.
17. Hylton House
18. Visits: M.S. Society  
Aykley Heads School  
Earls House Hospital
19. Care Training in  
the home: Mrs Coates, Frank Brady



APPENDIX 19BUDGET OF DURHAM COMMUNITY CARE

Budgets submitted and agreed with Manpower Services Commission Agents: The Boys Brigade, Consett	<u>1984/5</u>	<u>1985/6*</u>
Overall allowance from M.S.C.	£44,948.56	£50,006.20
<u>Capital</u>	1,083.00	-
<u>Revenue</u>		
Rent and Rates	1,550.00	1,300.00
Transport	600.00	1,630.00
Maintenance	470.00	130.00
Training	150.00	228.80
Statutory, telephone, insurance	596.00	1,296.00
<u>Staff Wages</u>		
F/T Organiser @ £118 p.w.	6,135.00	6,419.92
F/T Senior Care Helper @ £2.00	3,848.00	5,060.12
P/T (30 hours) Clerk/Typist	3,120.00	3,463.20
9 P/T (24 hours) Care Helpers @ £2.00 p.h.	22,464.00	24,935.04
N.I.	3,732.56	4,163.12
Agent Fees	1,200.00	1,380.00
	<hr/>	<hr/>
	£44,948.56	£50,006.20

\*revenue expenditure items adjusted  
in 1985/6 on the basis of the 1984/5  
actual costs.

APPENDIX 20Provisional Budget for Durham Crossroads Care Attendants Scheme(1986/87)

This budget is based on providing a service for between 45 and 55 families in the Durham City Administrative Area.

Capital

Initial Advertising Costs	150	
Office Furniture and Fittings	300	
Telephone Installation	100	
Telephone Answering Machine	100	
Protective Clothing	<u>40</u>	690

RevenueRunning Costs:

Rent and Rates )		
Lighting, heating and cleaning)	950	
Telephone rental and charges	690	
Postage and Stationery	270	
Printing	70	
Advertising	50	
Insurance (Office/Personal Accident)	40	
Crossroads Affiliation fee	85	
(Public and Employers' Insurance Cover included)	<u>      </u>	2,155

Staff:

Co-ordinators Salary (25 hrs @ £3.75)	4,875	
Co-ordinators NHI Contribution	500	
Co-ordinators Travelling 2,750 miles @ 20.1 p	553	
Care Attendants Salaries		
130 hours weekly at average 2.90 per hr.	19,604	
Care Attendants NHI Contribution	500	
Care Attendants Travelling approx 11,000 miles	2,211	
Clerical Assistant/Wages Clerk	<u>600</u>	28,843

Training

<u>500</u>	500
------------	-----

£ 32,143

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