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## The social costs and rewards of caring

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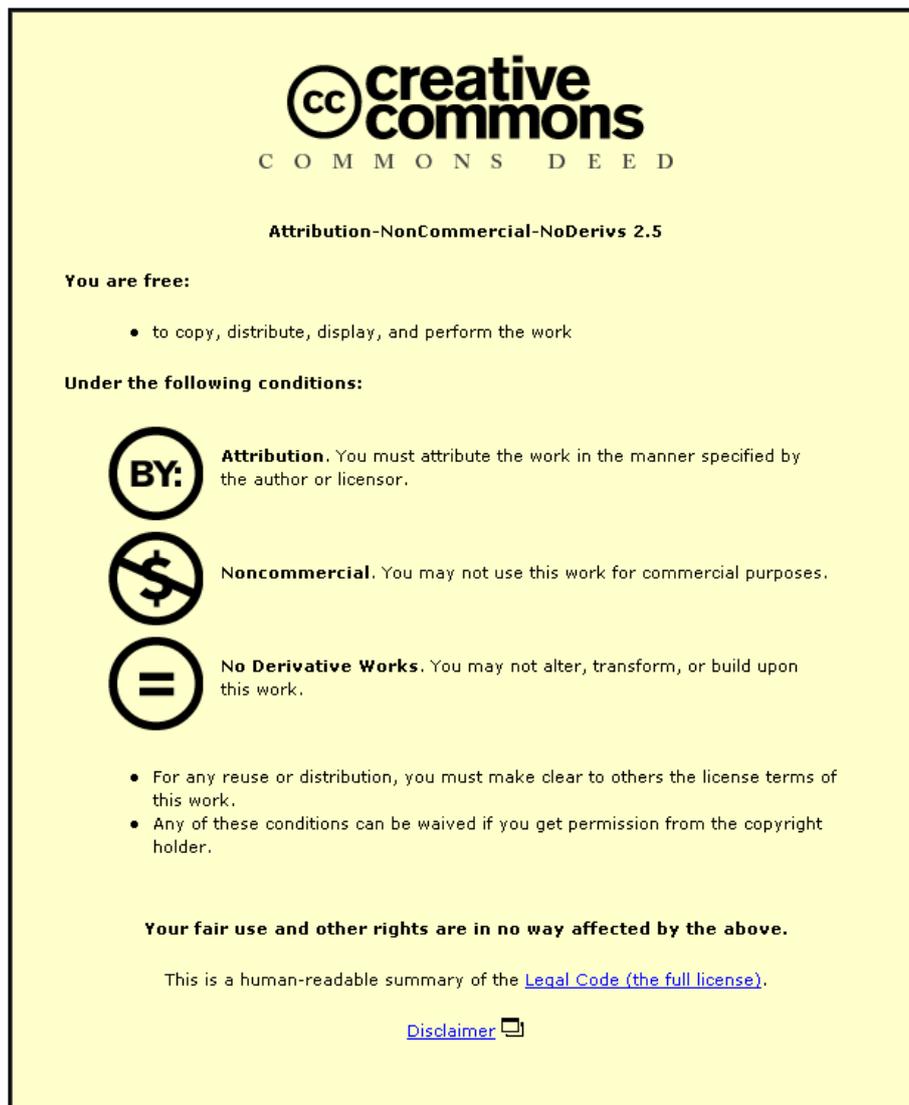
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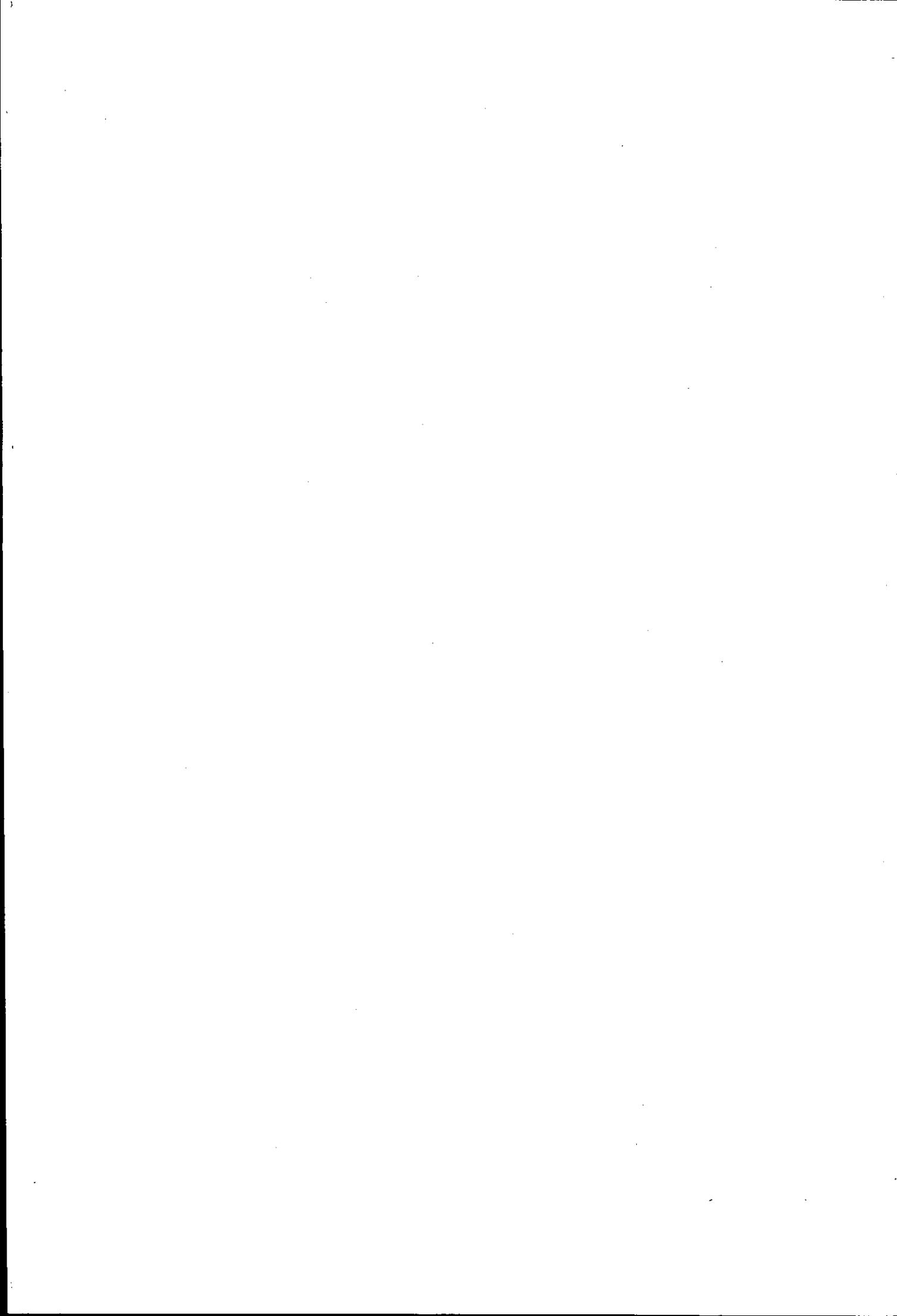
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THE SOCIAL COSTS AND REWARDS OF CARING

by

Dermot Clifford

A Doctoral Thesis

Submitted in partial fulfilment of the requirements  
for the award of

Doctor of Philosophy of the Loughborough University  
of Technology

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## ABSTRACT

Author: Dermot Clifford

Title: THE SOCIAL COSTS AND REWARDS OF CARING

This thesis is based on a study of two groups of carers. 199 valid interviews were completed with carers of frail elderly and of mentally handicapped children living in the community. The study was done in the South-West of Ireland.

The aims of the study were three-fold:

- (i) To examine issues in Community Care, currently under discussion in Britain and Ireland. Since very little research has been done on this subject in Ireland the comparative dimension is of special interest.
- (ii) To investigate the dynamics of caring through the comparison of the social costs and rewards reported by the two sets of carers.
- (iii) To fill some gaps in the literature, particularly in relation to the rewards experienced by carers.

The great majority of the elderly and mentally handicapped are cared for in the community in both countries. This developed to a considerable extent from a reaction to Institutional Care as it existed from Poor Law times to the end of World War II. But the option for Community Care which was so welcomed then has come in for criticism in its turn. Some have claimed that it boils down, in practice, to care within the family. Feminist writers further claim that the task of caring falls almost invariably to women who get very little support from any source. The accusation of promoting "care on the cheap" is levelled against Governments who use the rhetoric of family and community, to reinforce family values and force women into caring.

While recent literature stresses the social cost, to carers, comparatively little emphasis has been placed on rewards. Perhaps the rewards may be important in explaining why the majority of carers continue to carry out their task in the face of the heavy costs? Otherwise, how is one to account for the durability of this form of care?

The study is policy-orientated and points up the implications of the findings, with suggestions for increased support for carers from both formal and informal sectors.

Key words: CARER, CARED-FOR PERSON, COMMUNITY CARE COSTS, REWARDS OF CARING, DYNAMICS OF CARING

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BACKGROUND

In 1973, I conducted a study on Social Stigma among the recipients of three different income maintenance services in Tralee, Co. Kerry. This formed part of an M.Sc. degree in Social Administration at the London School of Economics which I sat in 1974. The study which included three hundred interviews was published in Ireland<sup>1</sup> and in Britain<sup>2</sup>.

On my return to Ireland, I became Secretary to the Diocese of Kerry and also Social Policy Advisor. I took up an additional post as part-time lecturer in Social Policy at University College Cork in 1975.

A study on Poverty had been carried out in the early part of 1974 in the Kerry Diocese and I helped publicise the findings at Seminars which were held in the ten towns in the Diocese<sup>3</sup>.

The elderly emerged in this study as the most deprived group. Their incomes were frequently below the poverty line, their housing tended to be old, run down and lacking in amenities such as running water, indoor toilets and so on. And a substantial minority were reported to be isolated and lonely.

This last fact took most people by surprise. Kerry prided itself on its good neighbourliness and community spirit. It had been taken for granted that nobody was left out of its strong networks of family, relatives, neighbours and friends. Furthermore, there were new statutory services emerging from the recently formed Health Boards and voluntary bodies were

being coordinated through newly formed Community Councils in almost all the towns. Many refused to believe that a large section of the elderly were lacking in human companionship.

So, in 1977, I undertook a further study into the question of Loneliness among the over 65s. A large sample was selected in the Diocese which includes all County Kerry and eleven parishes in County Cork. Four hundred and seventy eight interviews were completed; 15 per cent of the respondents said they were lonely "always" or "often" and a further 20 per cent said they were lonely "sometimes".

The study was intended to be action directed. The findings received national coverage in the press, radio and television over Christmas 1977. The main aim was to stimulate good neighbourliness and informal visiting in the first place and, in the second place, volunteers were to be trained to visit the frail elderly in their areas along the lines of Hadley, Webb and Farrell's *Across the Generations*<sup>4</sup>.

Pilot schemes were set up in schools and in parishes. I published articles in the two principal journals for priests and religious<sup>5,6,7</sup> and in the national and local press.

During 1978, I became interested in the work of voluntary organizations in England and attended the A.R.V.A.C. Conference in London at which Philip Abrams spoke on "Neighbourhood Care and Social Policy". I subsequently followed the development of his ideas and his research until his untimely death in 1981.

The most striking finding in the study on loneliness was the

relationship between loneliness and incapacity. The greater the degree of incapacity the more likely the old person was to feel lonely. It was this finding which led me to concentrate on the frail elderly.

During those years, I established links with the Statutory Service and was at regular meetings with the Director of Community Care, the Medical Officer of Health and the President of the St. Vincent de Paul Society - one of the main voluntary organizations engaged in the care of the elderly and the poor. Each year we organised a Seminar for all who were interested in Community Care in the area. Our guest speaker on one occasion was Clare Wenger, who presented research into the care of the elderly in rural Wales. This proved most interesting to me from a comparative point of view and I subsequently kept contact with the Research Unit at the University College of North Wales, Bangor.

My study of the frail elderly soon made me realise how much they depended on their carers. Indeed not only they depended on these dedicated people but the whole community depended on them. Were it not for them, the residential sector would most probably be swamped with demand for places.

In the early 1980s, I became aware of the impetus for social justice and equality in the area of Community Care in the British literature on Carers. The work of Land<sup>8</sup> and Finch and Groves<sup>9</sup> pointed out that the carers were almost always women and they were unpaid. What was more, they were frequently expected by society to sacrifice careers and work outside the home in order to care for elderly relatives or

handicapped children. As well as financial costs, there were heavy costs to their health also as they carried out the daily grind of caring with little or no help from husbands, children, relatives or neighbours. Occasionally, the rewards to carers were mentioned but the costs and injustice to women carers were what was mainly emphasised. Since no study of carers had ever been done in Ireland, I became curious to examine the attitudes of Carers here.

My interest in the handicapped resulted from taking up an invitation from the Franciscan Sisters of the Divine Motherhood to come and reside at their Home for the Mentally Handicapped at Beaufort, nine miles from my place of work in Killarney. I now added another job, that of Chaplain, to my other posts! But I soon became involved in the lives of the children, the staff and the parents who were encouraged to visit regularly. The complex included a school which was attended by children from the Home and others who came in buses as day pupils from a wide area round about. I published an article on the gifts of the handicapped and on their place in the Christian Community<sup>10</sup>.

The mothers were almost always the principal carers of the handicapped children and I soon realised the great need they had for support from family and community in their difficult caring role. Again, no study had been done on these carers in Ireland. In fact, very little had been published on the care of the handicapped here<sup>11</sup>.

It was from this background that the idea formed and grew of

a comparative study of the carers of the frail elderly and the mentally handicapped in the Diocese of Kerry. It combined my own two main areas of interest, it followed fairly logically from my earlier research and it allowed me to break new ground in social research in Ireland.

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CHAPTER 2THE IRISH CONTEXT

I shall now seek to situate the study within the Social Policy context of the Republic of Ireland. I shall briefly outline the historic background, the demographic patterns and the existing social services for the elderly and the handicapped, with special reference to the area in which the study was conducted.

Richard Titmuss<sup>1</sup> once compared the social services of a modern industrial society to a train journey. His point was that the social services are integral to a modern State and not "things apart" or of "marginal interest". "They are not things one sees out the train window, they are part of the journey itself". Continuing his analogy, the Irish train has, over the past one hundred and fifty years or more, run parallel to its English counterpart. It was under British rail until 1921. Although it is a much shorter train it has met with much the same problems as the English train, over-crowding, delays and breakdowns. In the very recent past, carriages have been removed. The Irish train drivers and passengers have always kept a close eye on the progress or otherwise of the British trains. Very occasionally, they have been ahead.

To fully understand the present day social services in Ireland, one has to know a little about the Poor Law Ireland Act 1838 and its subsequent history.<sup>2</sup> The new Poor Law Act of 1834 was imposed on Ireland. An Irish Commission had specifically recommended against its introduction but a visit by George Nichols was to reject all the recommendations

and introduce the Workhouse System throughout the land.

This was Ireland's first statutory social service and, in a short number of years, one hundred and sixty three workhouses had been built. As in England, the Workhouse System was modified over the years but to-day's social services for the elderly, handicapped, children and the mentally ill branched out from its main line. So too did the income maintenance services.

The Famine of 1846 and 1847 so overwhelmed the Workhouse System that police had to push back the starving crowds who begged for admission. A temporary relaxation of the workhouse test was forced upon the Poor Law Commissioners and outdoor relief was granted as a temporary measure through the Irish Poor Relief Extension Act of 1847 or the Soup Kitchen Act as it was popularly called. In fact, this temporary concession was never revoked and the outdoor relief of that time became the Home Assistance service when the Irish Government took over in 1921. This continued to be the main income maintenance system for the very poor until it was further modified by the Supplementary Welfare Act 1975. With the foundation of the Irish Free State in 1922, the workhouses were re-named County Homes and became the residential homes for the elderly poor in each county. It was not until 1968 that the Inter-Departmental Committee on the Care of the Aged advocated that "the concept of County Homes should be abandoned".

In the health area the pressure from the famine accompanying cholera brought about a Dispensary System for the whole

country. The Medical Charities Act of 1851 set up seven hundred and twenty three Dispensary Districts each having a General Practitioner. This gave the sick poor free medical care and free medicines at their homes or at the dispensary. The very sick were moved to Fever Hospitals, which were in or near the Workhouses. This service remained virtually unchanged until 1970 when the Health Act of that year provided a Choice of Doctor Scheme. From the dispensaries, a Domiciliary Midwifery Service developed in 1859 which was not subject to the Workhouse Test. This, in turn, had some influence on the development of the State Hospital Service and the area of preventative health. County Infirmarys, small local hospitals, grew side by side with Workhouse Union Hospitals. The Workhouse Hospitals were open to the sick also without the Workhouse Test from 1862 onwards.

The break-up of the mixed workhouse took place somewhat earlier in Ireland than it did in England with the boarding-out of children through the Relief of the Destitute Poor in Ireland Act of 1862. The mentally handicapped began to be rescued from the workhouses also with the founding of Stewart's Hospital in Dublin in 1869. It still cares for this group.

The services which branched out from the mainline Poor Law received minor adjustments when the Irish Free State was founded in 1922 and occasional re-adjustments up to 1970. The 1960s saw the first up-turn of the Irish economy for more than a century. This was the result of a boom in the world economy at the time and also because of the

coming of foreign investment and foreign industries to Ireland. Emigration, which had been a constant drain on the population since the Famine, began to be reversed for the first time in the early 1970s. From 1973 to 1979 there was a net immigration with the return of many who had gone to England or America in the forties and fifties. The population, which had consistently fallen from 1847 to 1971, began to increase for the first time. Some of the newly created wealth was invested in the Free Education Scheme 1966 and the Free School Transport Scheme 1967 for the Post-Primary sector.

But it was in the area of Health that the most important developments took place from the point of view of this study. The Health Act 1970<sup>3</sup> rationalised the health and community services. It took under its wing the General Hospitals, the Special Hospitals for the handicapped and the mentally ill and the whole area of Community Care which includes the personal social services for the elderly, the handicapped and the mentally ill. The 1970 Health Act was based on the recommendations of four separate Reports : 1. The White Paper on "The Health Services and their Further Development", 1966<sup>4</sup>; 2. The Commission of Inquiry on Mental Handicap 1965<sup>5</sup>; 3. The Inter-Departmental Committee on Care of the Aged 1968<sup>6</sup>; 4. The Commission of Inquiry on Mental Illness 1966<sup>7</sup>.

It is interesting to search out the references to Community Care in these influential documents. The White Paper on "The Health Services and their Further Development",

which would seem to have been the blue-print for the 1970 Health Act, said:

*"the Government's general aim is to encourage old people to stay at home and to endeavour to ensure that assistance will be available where needed to enable them to do so without causing hardship to the aged or too heavy burden on their relatives. Primarily, this assistance will form part of the ordinary pattern of the health services ..... and this should adequately meet the medical and allied needs of most old people."*

The Commission of Inquiry on Mental Handicap had this to say:

*"It is accepted as a general principle that community care (i.e. care provided outside residential centres) is therapeutically better for a handicapped person, permits of a fuller development of his personality and avoids the difficulty of adjustment to normal life which is frequently experienced after prolonged care in a residential centre. It is desirable, therefore, that community care should be provided so that, where possible, the mentally handicapped can be retained in their own homes or in suitable family care."*

The Inter-Departmental Committee on Care of the Aged was unequivocal on the need for community facilities and the avoidance of institutional care:

*"The vast majority of the aged live in the community and many families make great sacrifices to look after their aged relatives. Even with such sacrifices it is beyond the power of the family in most cases to provide for all the needs of the aged - these needs can be met only by a partnership between the family and the voluntary organizations ..... so the Committee's recommendations regarding the services which should be provided are based on the belief that it is better and probably much cheaper to help the aged to live in the community than to provide for them in hospitals or other institutions."*

The Report of the Commission of Inquiry on Mental Illness, 1966, recommended a movement away from custodial care to "rehabilitation and restoration to the community as far as possible". In this way they were giving official

recognition to a trend which was already well under way as the total number of patients in Mental Hospitals had fallen from 21,075 in 1958 to 15,392 at the time of the Report with a corresponding increase in out-patient treatments over the same period.

Both the Committee on the Care of the Aged and the Committee on Mental Handicap were well aware that some institutional care would continue to be needed. The Care of the Aged Committee advocated moving away from the large County Home institutions and the provision of Welfare Homes for the ambulant with Long-Stay Hospitals for those who needed such long-term care. They recommended that each area should have a Geriatric Assessment Unit. Likewise, the Commission of Inquiry on Mental Handicap realised that extra places would be needed in residential homes for children who needed to have some early training or schooling.

There was a second important emphasis in all these Reports. This was the role of the voluntary bodies. The White Paper on the Health Services stated:

*"Voluntary Organizations can often provide the most effective home aid. It is important that their efforts should be encouraged by support and assistance from Public Authorities, and, if all the services are to be provided effectively then there should be close co-ordination between those working voluntarily and appropriate Public Officials."*

The Report on the Care of the Aged recommended that:

*"Local Authorities should take an active role in encouraging voluntary bodies providing services for the aged and should support them financially."*

It also recommended that Social Service Councils should be set up to achieve co-ordination of statutory and voluntary services and disseminate information in regard to the available services and should foster the development of community services.

A further Report by McKinsey, "Towards Better Health Care" 1970/1971<sup>8</sup>, recommended that the Programme Manager for Community Care would "communicate the nature of the target of the community care programmes and agree with the heads of voluntary agencies on the funds they are to receive to ensure that there is agreement about specific contributions the voluntary agencies will make to reach these targets and to encourage the effective operation and co-ordination of these organizations".

The voluntary sector<sup>9</sup> has always been extremely strong in Ireland. The Religious organizations and others have played a major part in the provision of services for the poor and the elderly and the disabled. After the 1970 Health Act many areas have voluntary Care of the Aged Committees, meals on wheels services, visitation services and so on. These are frequently funded by the Health Board to provide these services.

In the area of mental handicap, the major part of provision is through Religious Orders who have run the residential homes and very often provided the day-care services as well. These Orders have usually had the support of groups like Parents and Friends of the Mentally Handicapped. The Orders have received most of their funding from the Department of

Health since the 1970 Health Act. Sometimes, they employ Social Workers who are again funded through the Department of Health. Members of these Religious Orders would be involved at the policy-making level within the Department of Health. It is they who have pioneered advances in the service including the provision of small group homes, workshops and training centres and the supervision of flats for adult mentally handicapped.

A Report commissioned by the National Economic and Social Council and carried out on their behalf by Sheila O'Connor, "Community Care: an Overview",<sup>10</sup> summed up the assumptions which ran through all the Reports mentioned above.

- "(1) Community Care is better than institutional care;
- (2) Community Care is probably cheaper;
- (3) The voluntary sector has a significant contribution to make and it should be fostered."

She goes on to point out that the commitment to Community Care did not result in the commitment of increased resources in that direction. The share of the total expenditure actually fell from 23.4 per cent in 1976 to 22.2 per cent in 1985. During that time, the share of the General Hospital Programme increased from 48 per cent to 51.2 per cent. However the programme for the handicapped, including mentally and physically handicapped, rose from 7.6 per cent to 9.9 per cent during the same period. It is generally recognised that the General Hospital and District Hospital systems have been over-used and that, for this, and, because of the employment they give, they continue to take the lion's share of the

available finances. However, when local hospitals are closed, even small sub-acute hospitals, there is usually strong public protest. The people see the closure of their hospital as a blow to the health services at local level. But when cutbacks took place in the health services over the past eighteen months, far from an extension of Community Care, there were severe cutbacks also in the Community Care sector.

#### ACTUAL SERVICES FOR THE ELDERLY IN THE COMMUNITY

The two main services relevant to the elderly in the community are those of the Public Health Nurse and the Home Help service. There is of course the General Practitioner service which replaced the old Dispensary Doctor with the Choice of Doctor Scheme. All elderly who have the non-contributory old age pension are entitled to a medical card and to free visits from their general practitioner and to free drugs from the chemist. 40 per cent of the population as a whole have these free services at the present time.

The social workers who are employed by the regional Health Boards tend to spend all their time with child care and with family problems. There are some social workers employed by the Religious Orders in the mentally handicapped area. But the Social Work Service does not apply to the elderly

In their case the public health nurse is the key person.

She not only gives nursing care where necessary but organises home help in many cases and acts as the referral agent to hospitals, day care centres and welfare homes. The public health nurses are a long established group and now number 1,153 with additional superintendent public health nurses in each County. The public health nurse visits 3 per cent of the over sixty fives throughout the country. The recommended ratio is one to 2,616 population according to the Working Party on the Workload of Public Health Nurses 1975. The ratio varies greatly from one Health Board area to another. For example, it stands at one to 2,233 in County Leitrim and at one to 3,014 in Dublin City. The ratio in the Southern Health Board area, where this study was done, is one to 4,191 which is the highest of all the Health Board areas in this regard. These variations would seem to have very little to do with variations in need. The reverse may well be the case. O'Connor stated that they were "markedly under-staffed in some areas". With the recent cutbacks in the health services the training of public health nurses has almost come to a standstill.

#### THE HOME HELP SERVICE

The 1970 Health Act empowered but did not require Health Boards to provide a Home Help Service. Prior to 1970, some local authorities operated their own schemes but on the introduction of the 1970 Health Act, the Minister for Health allocated funds for this purpose to the Health Boards. Voluntary agencies have been very much involved in this area also. It would seem that considerable

flexibility is allowed in the manner in which the Home Help Service is organized in the different areas.

In practice, almost all the home helps are part-time. In some of the Health Board areas, neighbours are given a small payment to provide a lunch and do some housework for an old person next door. In the Southern Health Board area in which this study took place, a local woman, usually a housewife, has a group of four or five whom she visits a few times a week. There is a Home Help Organizer in the area who arranges for courses with the Vocational Educational Committee for such home help personnel. The public health nurse is the one who organises and supervises the Scheme in other Health Board areas. In 1983, 2 per cent of those over sixty five were receiving home help and 75 per cent of the recipients were living alone. O'Connor sees the Home Help Service as inadequate. She found it particularly difficult to get precise information on the extent and nature of the help given by voluntary bodies, volunteers and neighbours. She found that the level of training, support and remuneration were uneven and unsatisfactory. There were large variations in resource distribution. As well as this, she pointed out, "at present, the Home Help Service is available almost exclusively to elderly people living alone. There is considerable reluctance to provide the service to people living with relations. This reflects the widespread reluctance, not only in Ireland but also in Britain, to support caring relatives".<sup>12</sup>

There are a number of other services worth mentioning briefly. The over sixty sixes who are in receipt of the non-contributory old age pension are entitled to free travel on public transport, to free television licences and to free rental on their telephones. There are fuel allowances and electricity allowances for those who live alone. In these areas, I think that the Irish train is somewhat ahead of its British counterpart.

The most recent Report on the care of the aged came from a Working Party appointed by the Minister of Health in 1986 with the following terms of reference:

- "Accepting that the overall objectives of services for the elderly are -*
- (a) to enable the elderly person to live at home, where possible, at an optimum level of health and independence,*
  - (b) to enable those who cannot live at home to receive treatment, rehabilitation and care in accomodation and in an environment as near as possible to home"*

*the Working Party is asked to review:*

- (i) the role and function of existing health and welfare services in serving these objectives*
- (ii) the appropriateness of existing health and welfare services*
- (iii) the comparative effectiveness, efficiency and cost of alternative models and settings*
- (iv) the planning norms for services both residential and community."*

The membership of the Working Party included Civil Servants, medical, psychological and social work personnel and administrators of Community Care in the Health Boards, a geriatrician and a representative of the National Council for the Aged. Their findings were presented to the Minister for Health in October 1988 with an accompanying

letter which included the following three points:

- "(a) that the dignity and independence of the elderly can best be achieved by enabling them to continue to live at home with, if necessary, support services provided by the State;*
- (b) that when ill or disabled, the elderly are entitled to the same standard of treatment available to the rest of the population even if services have to be organized in ways that meet particular needs;*
- (c) that when admission to long term care is unavoidable, such care should be of the highest standard and should respect the dignity and individuality of the elderly person."*

This Report, *The Years Ahead: A Policy for the Elderly*,<sup>13</sup> endorsed fully the commitment of the 1968 Report mentioned earlier to the desirability of Community Care but it adverted also to the difficulties experienced by carers and it pointed out ways in which Statutory services should be expanded to give more support to carers. It did not advert to O'Connor's criticisms of the services although it proposed detailed policy and financial improvements for the elderly and their carers.

#### THE KERRY DIOCESE : AREA OF THE PRESENT STUDY

The Diocese of Kerry includes all of County Kerry with its population of 120,000 and ten rural parishes of County Cork with a population of 20,000 approximately. It is situated in the south west of Ireland and is within the Southern Health Board region. Together with its central area (the two main towns of Tralee with its population of 20,000 and Killarney with a population of 8,500) there are three peninsulas, Dingle, Iveragh and Kenmare, and

Castletownbere. These are very scenic areas and very popular with tourists but, in common with the greater part of the West and North West of Ireland, these areas have suffered greatly from unemployment and emigration and migration to the cities ever since the Great Famine. The population of County Kerry has constantly declined since the Famine. In 1901 it was 165,726; in 1926 it had fallen to 149,127 and by 1971 it was at an all time low of 112,722. During the next decade it increased for the first time to 120,281 in 1979, but even when it increased, it was the two main towns of Tralee and Killarney and their environs which increased, while the three peninsulas continued to lose, if at a slightly slower rate.

Despite the high birth rate throughout all the years, emigration depleted the ranks of those between 18 and 25 one generation after another. This leads to a disproportionate percentage of over sixty fives in many areas. In Ireland as a whole 10.7 per cent of the population are over sixty five. In the rural counties it is much higher. County Leitrim has 17.6 per cent over sixty five, County Mayo 15.9 per cent, County Roscommon 15.6 per cent, County Sligo 14.2 per cent, County Donegal 14 per cent, County Kerry 14 per cent. County Kildare, on the other hand, which is situated near Dublin has only 7 per cent over sixty five. Within County Kerry, which has 14 per cent over sixty five, there are great variations from the towns to the rural areas. In Dingle peninsula, 16 per cent are over sixty five,

in Iveragh peninsula 18 per cent are over sixty five. The small parish of Tahilla, near Sneem, has 28 per cent. The south coast of England or the retirement areas of Florida would find it difficult to match this figure. When one adds to this the fact that County Kerry has the fourth lowest density of population in Ireland one begins to have an idea of the challenges which face the delivery and provision of social services in these far-flung parts. Most of them do not have train services or even regular bus services. Many of the elderly live a long distance from towns and from their G.P.s. In the Western Health Board, for example, two fifths of the elderly live more than five miles from their G.P. This would be true also of much of the Southern Health Board although I have not been able to find the figure for it. Voluntary bodies also tend to be centred in towns and services like meals-on-wheels and transport to and from day-care centres or visitation turn out to be extremely expensive. The studies of Wenger and her co-workers in North Wales describe similiar problems of distance and accessibility.

Apart from a few passing references and the most recent Report, very little has been mentioned about the need for supporting the carers in the Irish literature. It has been acknowledged that families very often make great sacrifices to look after an elderly or handicapped member, but nowhere was the support of the carer mentioned as a priority. Neither was there any reference to the fact that it is mostly women who are carers. It was pointed out by O'Connor that the Home Help Services in particular

are centred almost exclusively on the elderly who live alone. She also points out that "basic to the promotion of individual welfare is information on the range of needs, not only of dependent people, but also of those who are providing informal care, in particular, families. Information on dependent people in terms of services that facilitate community living is limited. Information on informal care and on the motivation and expressed needs of those who provide it has not been collected until very recently. Similarly, information on the voluntary sector in Ireland is limited."<sup>14</sup>

In fact, in 1987, the National Council for the Aged, an organization set up by the Irish Government, examined the extent and nature of caring of the elderly and embarked on an in-depth study of a number of carers of the elderly.<sup>15</sup> No comparable study has yet been attempted on carers of the handicapped. In respect to the literature at any rate, the Irish train has fallen greatly behind its British counterpart. I am happy, however, to be on board and urging the driver to speed up a little!

NOTES

1. Titmuss, R.M., 1958, *"Essays on the Welfare State"*, Unwin University Books, London, Preface.
2. Burke, Helen, 1987, *"The People and the Poor Law in 19th. Century Ireland"*, W.E.B. (Women's Education Bureau), England, for an account of the development of social services from the Poor Law Act (Ireland) 1838 which was, in fact, the first public social service and whose foundations are still discernible in the services to-day.
3. Hensey, B., 1972, *"The Health Services of Ireland"*, 2nd. ed., the Institute of Public Administration, Dublin, covers the different developments in health policy up to the 1970 Health Act.
4. *The Health Services and their Future Development*, 1966, Government Publications, Stationery Office, Dublin.
5. *Report of the Commission of Inquiry on Mental Handicap*, 1965, Government Publications, Stationery Office, Dublin.
6. *The Care of the Aged*, 1968, Report of an Inter-Departmental Committee, Government Publications, Stationery Office, Dublin.
7. *Report of Commission on Mental Illness*, 1966, Government Publications, Stationery Office, Dublin
8. *Towards a Better Health Care*, 1970, McKinsey & Co. Dublin.
9. See *Directory of Social Service Organizations*, 1980, National Social Service Council, Dublin, for a list of national and local voluntary organizations which help in this field.

10. O'Connor, S., *"Community Care Services An Overview: 1987"*, National Economic and Social Council, Dublin.
11. *Survey of Workload of Public Health Nurses, 1975.* Report of a Working Party, Government Publications, Stationery Office, Dublin.
12. O'Connor, S., 1987, op.cit., p.54
13. Report of the Working Party on Services for the Elderly (1988), *"The Years Ahead: A Policy for the Elderly"*, Government Publications, Stationery Office, Dublin.
14. O'Connor, S., 1987, op.cit., p.33
15. National Council for the Aged, *"The Caring Process : A Study of Carers in the Home"*, To be published. This study of carers will provide basic data on carers of the elderly: who they are, their number and socio-economic status, their relationship to the person cared for and how and why they became carers.

CHAPTER 3REVIEW OF THE LITERATURE

Community Care like other concepts in Social Administration such as social class, alienation, social stigma, loneliness and poverty is elusive and difficult to define and make operative. Perhaps its vagueness is the cause of its long-standing popularity on all sides. When Douglas Houghton stated in the 1950s that "There are three institutions in Britain about which no hard word can be said, the Crown, the Church and the National Assistance Board", he could, with a little foresight, have included Community Care.

Part of its strength and most of its weakness comes from the pentecostal quality which enables it to be understood by very diverse interest groups, each in its own language and accepted on its own particular terms. It means all things to all people and very particular things to some. The result is an ideal which all accept, but a reality which has not even remotely lived up to the ideal thirty years after it began to emerge as an alternative to institutional care.

Nevertheless, the concept has been clarified and developed since it was popularised in relation to the Mental Health Act 1959. And it has been tested in practice in a number of local projects carefully monitored and yielding promising results. Even though it has been a slow developer its time may yet come. Its retarded development

was due in no small measure to its near starvation of public finance.

Community Care began as a reaction to and a move away from the grim Poor Law institutions which became increasingly unacceptable after World War 11. Perhaps, the horror aroused by Nazi concentration camps played a part in the wish to replace large institutions for children, the mentally ill, the handicapped and the elderly. The publication of Townsend's *"The Last Refuge"*,<sup>1</sup> the scandal at Ely Hospital, Cardiff, Bowlby's *"Child Care and the Growth of Love"*<sup>2</sup>, Robb's *"Sans Everything"*<sup>3</sup>, Morris's *"Put Away"*<sup>4</sup> all confirmed the belief that the sooner such institutions were demolished the better.

Webb and Wistow<sup>5</sup> rightly situate this move within a more complex framework: "The first post war commitment was to move away from the institutional heritage of the Poor Law by building new smaller homes. The second development was the expansion of domiciliary and day-care services: small dwellings for one or two person households and sheltered housing, as alternatives to residential homes. The third was concern to reduce the need for long-stay care of the elderly in hospital and to avoid the silting up of beds in both acute and geriatric wards. In the case of mental illness and handicap, this issue of hospital beds was at the heart of policy from the very beginning." Then there was the further objective of avoiding unnecessary public expenditure on formal services.

One ought also to mention the discovery of the phenomenon

of "institutionalisation" <sup>6</sup> as a kind of social paralysis which grows on the inmates of large institutions after some years confinement. So there was, what Webb and Wistow describe as a "confluence" of factors, at work in the proposed move from institutional to Community Care.

As early as 1961, Titmuss<sup>7</sup> was alerting the public to the dangers of sending patients out of hospitals into a community which did not have anything like adequate domiciliary services. They were "off the books" as far as the health services were concerned but they were often abandoned and uncared for. In a purple passage Titmuss described Community Care as "the everlasting cottage-garden trailer". He worried, "we may pontificate about the philosophy of Community Care; we may feel righteous because we have a civilised Mental Health Act on the statute book but unless we are prepared to examine at this level of concrete reality what we mean by Community Care, we are simply indulging in wishful thinking. To scatter the mentally ill in the community before we have made adequate provision for them is not a solution; in the long run not even for H.M.Treasury..... At present we are drifting into a situation in which by shifting the emphasis from institution to community - a trend which in principle and with qualification we all applaud - we are transferring the care of the mentally ill from trained staff to untrained staff, ill-equipped staff or no staff at all."

An important clarification of the concept of Community Care

came with Bayley's<sup>8</sup> distinction between Care in the Community and Care by the Community. This was to give, as he put it, "more substance" to the term. Care in the Community was the Government's official services operating outside large institutional settings, conceived of and operated independently of the people who happened to live in the area round about. Care by the Community meant that ordinary people in the community were part of the caring process and were involved as family, neighbours, voluntary bodies or volunteers. Bayley presented a comprehensive four tier concept. "A view of Community Care which takes account of the complexity of human organization and the realities of our political and administrative system entails consideration of society at four levels: (a) the client and his family which merges into (b) the social network of family, kin and neighbours (c) the social worker and the local authority services which <sup>or may</sup> ~~may~~ not include (d) some form of residential care". Here we have a continuum of care between informal and formal sectors of Care and a recognition that residential care formed an integral part of any comprehensive service. Bayley hoped to develop a sensitive interweaving of formal and informal but possibly underestimated the difficulties involved.

Abrams<sup>9</sup> was soon to deny that there was any such continuum, In fact he maintained, in his influential article of 1977, that the formal system tended to undermine and erode the informal. He cited various studies to

conclude that community or neighbourhood care always boiled down to care by family or kin. Neighbours came a very poor third according to Abrams. He was critical of the romantic notions of natural good neighbourliness as exemplified in the Bethnal Green of Young and Wilmott,<sup>10</sup> attributing it to the fact that they were more often kin than neighbours. Indeed the same charge has been made about the account of mutuality in the Ireland of the 1930s in Arensburg and Kimball's classic study, where again, many of the neighbours who exchanged help were in fact kin.<sup>11</sup> Abrams maintained that Community Care just does not happen in the modern setting. Although he modified this view in the light of his later studies,<sup>12</sup> Abrams' challenge in this area was valuable since it forced social scientists to question any easy assumptions about the automatic existence of Community Care. Henceforth it could not be presumed to exist unless proven by research. For Abrams<sup>13</sup> the situation was that .... "we must start off from the finding that in the typical social setting of contemporary British society, Community Care is typically volatile, spasmodic and unreliable; very much not a social fact."

He saw the only realistic prospect for Community Care as being within family and kin in the first place and then within moral communities such as Churches. And the motivation for such care, he claimed, would be empathy, sense of duty and reciprocity. This latter resulted in a "calculative involvement" on the part of helpers. "Reciprocity is at the heart of the caring relationship

in Community Care. One can only wonder at the extent to which the question of what the caring agent gets in return for care given has been neglected in earlier research. "*Across the Generations*" takes a useful step in this direction as far as volunteers working with the elderly are concerned. And there are other indications that caring for others can be an important means of obtaining care for oneself for certain groups - especially the chronically underemployed middle aged of both sexes - and that members of such groups are thus available as potential caring agents. But we need to know a good deal more about the rewards for care."

Abrams thus rejected the idea of Care by the Community as an army of neighbours automatically rallying around. This simply does not happen any more in a culture where privacy is such a prized value. So he here, for all practical purposes, narrowed down Community Care to the family in the first instance and after that kin and finally moral communities. The social division of care had gone a further step.

Simultaneously with Abrams, Moroney<sup>14</sup> undertook a very significant study of Community Care policies in Britain and concluded also that the family bore the main burden of Community Care. He examined the existing data on families with frail elderly dependents and mentally handicapped children and supplemented this information with interviews with academics, social service officials and families. He posed three fundamental questions:

(a) Are families less able and willing to care for their dependent members than they were? (b) If more families want to get rid of their dependent what are the likely costs in terms of social policy? (c) How far is social policy itself influencing family attitudes and responsibilities?

His conclusion was that the social services in Britain were not supporting carers within the family. They tended to "substitute" for it when it was absent or when it had broken down under the burden. The residential sector swallowed up the major part of the budget for a small percentage of the elderly and mentally handicapped while domiciliary services were directed predominantly to those who had no family network. Meanwhile, the families who were struggling to look after a dependent person were given no help until their capacity to continue had been eroded or collapsed altogether. The social services behaved somewhat like a life-guard who looked on from the shore while one swimmer struggled to rescue another and only came to their assistance when both had gone under. He then fished them both out and undertook to revive them.

In fact, Moroney<sup>15</sup> subsequently expressed the view that the social services penalised families if they cared and rewarded them when they ceased caring by taking over full time care of the cared-for person and sometimes the carer as well. He laid the blame in part on the social worker's training on the pathology of the family, but also on the deep-rooted

ambivalence about the family's role. This conclusion was borne out by the Equal Opportunities Commission (1982)<sup>16</sup>: "There is considerable evidence to suggest that the failure to consider family needs as well as those of the dependent creates such problems for the carer that she may eventually be unable to continue caring. Isaac's study revealed that less than half of all patients admitted to a geriatric hospital in Glasgow were hospitalised solely for medical reasons; the ill-health of the carer, caused by the prolonged strain of caring, or her inability to give up work, were more significant factors."

When Community Care, understood as care within the family, became part of the conventional wisdom in the early 1980s, the Conservative Government seized upon it eagerly. Mrs. Thatcher and her Ministers quickly assumed the high moral ground with exhortations to self-reliance, non interference by the State in the family domain and in a short time their moral tone was higher even than that of the bishops ! For example, one distinguished prelate only avoided being sent to Coventry by the fact that he happened to be the Bishop of that city already when he pointed out the State's obligations to the deprived. Mr. Patrick Jenkins<sup>17</sup> articulated the Conservative Government's philosophy of Community Care for him, "There has been a tendency to believe that as statutory services grow, as more services are provided by the public authorities, so the community can safely entrust their cares and their concerns for

the elderly and others in need to the town hall and Whitehall and need not themselves bother much. I was a little saddened to see a letter in 'The Times' last week from a distinguished prelate arguing precisely this fallacy. He argued that the nation's failure to afford the level of statutory services we might wish betokened a lack of Christian compassion on the part of the authorities. He simply could not be more wrong. His letter seemed to me .... to (say) .... that caring is the job of the State and not of the people..... The primary responsibility rests in the community; the statutory services are there to provide a framework, a back-up and special help in particular circumstances. It really is not and cannot ever be the other way round - the statutory services as the central provider with a few volunteers here and there to back them up. That simply does not represent the reality and we delude ourselves if we think that that's what it could or should be."

Here one has come from the acknowledgement of the fact that most care of dependents actually comes from within the family to the assertion that the family ought therefore to do all the caring. Community Care as located in the family then becomes a lofty excuse for the State's cutting back on services all-round and ignoring carers until they qualify for "special help in particular circumstances".

Mr. Jenkins spelled out this philosophy even more clearly on another occasion.<sup>18</sup> "The Government's approach to the

personal social services is founded on the simple fact that the frontline providers of social care always have been and will continue to be, the family and the community." And according to the Prime Minister herself ... "it all really starts in the family, because not only is the family the most important means through which we show our care for others. It's the place where each generation learns its responsibility towards the rest of society... I think that the statutory services can only play their part successfully if we don't expect them to do for us things that we could be doing for ourselves." Walker<sup>19</sup> notes that this ideology has been translated directly into policy towards the elderly: "It is the role of public authorities to sustain and where necessary develop - but never displace informal and voluntary care and support. Care in the community must increasingly mean care by the community."

So by the late 1970s "Community Care" had come to be identified very much as family care. The 1980s were to usher in another searching analysis of caring in the work of a host of feminist writers beginning with Land<sup>20</sup>, then Finch and Groves<sup>21,22</sup> and continuing up to the present time. These writers bring the debate from the social division of caring within the community to the sexual division within the family. Here one finds that, for a variety of reasons, the main burden of caring almost invariably falls on the shoulders of a female carer. Our detective work to discover the "real carer" has taken

us from vague notions of community, to the family and finally to a woman within the family. Had we borne in mind the ancient rule of thumb for readers of detective stories, "cherchez la femme", years of searching could have been avoided ! While this obviously is an oversimplification, it does strip down the notions of Community Care to its essentials. This helps to clarify. Research does redress the balance somewhat in favour of family members, spouses and other relatives, neighbours and friends.

The main arguments of the feminist writers are still valid. The majority of carers are women, they do not generally get the degree of help which they ought from family members, from neighbours or from domiciliary services. Their labour is largely unpaid or poorly acknowledged. Welfare payments, where granted to carers, are mere tokens of the work done. Graham<sup>23</sup> summed up the carers' contribution; "it is only visible when it is not done".

It is surprising now to find that there was so little attention paid to the social and emotional costs to the carers. Part of the reason was that the emphasis in the care of the elderly was on elderly being in institutions or living alone in the community. It took a long time to realise that the majority of the very frail elderly were being cared for in the family. Titmuss<sup>24</sup> did advert to "hard pressed daughters who may themselves be pensioners at nearly retirement age" and

Abrams<sup>25</sup> wrote of carers who "experience anger and frustration" and he advocated urgent study of the needs of carers which he described as "peculiarly unexplored territory".

Seldom has the call for research and clarification been met so swiftly, though Abrams did not live to see more than the beginnings of the analysis and research on the needs of carers and on the social costs and rewards of caring which came mainly from feminist writers in the 1980s. This analysis situates the joys and sorrows of carers within the overall context of injustice to women within the family, in the workplace and within Western society generally. This injustice is deeply rooted in the culture and traditions of Western societies. These traditional notions of family and community no longer correspond with the reality of life in urban settings, but social services and income maintenance services still operate on the assumption that nothing has changed.

Finch and Groves and others claim that the assumptions shared by politicians and policy makers in relation to the family are still based on the Judeo-Christian model of family. There is also the "cultural designation" of women as the natural carers and this remains very strong. The converse is that men are not expected to act as carers. It is not generally assumed that they will be able or that they ought to be able to look after their elderly or handicapped relatives. The financial dependence of

women on men within the family is another result of these outdated assumptions about the role of women and this applies particularly to female carers who are frequently forced to forego work outside home because of their caring role. Caring thus boils down to unpaid labour in the home. Thus the word "community" is for Wilson<sup>26</sup> "an ideological portmanteau for a reactionary, conservative ideology which oppresses women by silently confining them to the private sphere without so much as mentioning them... I suggest that we abandon the word community altogether - it is only one of the veils of illusion in which we are cocooned."

The State, through its income maintenance policies and its domiciliary services, the argument continues, serves to reinforce traditional ideas of family, community and women's dependent role. One is back to something very like the philosophy of the Conservatives on the obligation of the family to care, except that the family now reads female carer. Finch and Groves<sup>27</sup> expressed it as follows: "Thus community policies ... can easily become policies which create a moral imperative to care, imposed upon women to whom nature and chance have assigned a frail or handicapped relative. Such a situation is clearly disadvantageous to women in terms of the promotion of equal opportunities." The consensus of feminist writers is that the model of family on which present-day social policies are based is as outdated as the notion of "village life" as it is remembered and romanticised as the cosy community

with personal relationships, constructive methods of social control, the passing on of wisdom between the generations, of mutual respect and of patriarchal authority. Wilson<sup>28</sup> relates these ideas to the sociology of Talcott Parsons on family and community and the Chicago school generally which postulate a polarity between family values and urban values and which in turn are reflected in Parsons' description of division of roles within the family between husbands and wives. The man is moulded by the rational formal world of work which he inhabits while the woman's role is one of warmth, feeling and the intimacy of the mother and home-maker. This has led to the notion that women are "natural" carers while men are neither suited by nature or training to the caring role. Wilson describes this view as a "deeply conservative view of a necessary polarity between the sexes" and says it was already fully fledged in the Victorian period. Because of this antiquated kind of thinking she suggests that the concept of community as used by social administrators, policy planners and politicians "is riddled with reactionary implications especially with a vision of family which is incompatible with women's liberation."

The Equal Opportunities Commission came to much the same conclusion. It stated: "In recent years a number of important research studies have ... examined the reality of Community Care and the demands placed upon the carers. These have been reviewed in two earlier publications, *"Caring for the Elderly and the Handicapped"* and *"Who Cares*

*For the Carers?"* It is clear from the evidence presented in these, firstly that the costs (physical, social and emotional) to the carers are often very great and secondly that these costs are by no means evenly distributed across the community. The majority of carers are women, who are often coping alone with severely dependent elderly relatives to the detriment of their own health, their standard of living and their social lives. Many carers receive little help from other family members or the community and most receive little or no support from services. In the face of an increasing burden of dependency between now and the end of the century, it is essential to ensure that the available resources are used to the best advantage. This should not mean exploiting those individuals who are prepared to care."<sup>29</sup> The Commission went on to describe the cultural expectations which regard the man's wish to remain at home and care for a dependent relative and the woman's wish to work outside the home rather than care for a relative as equally "abnormal". "To what extent", asks the Commission, "are society in general and the Health and Social Services in particular, re-inforcing and perpetuating traditional values and social roles in caring relationships and is this working to the detriment of women carers?"<sup>30</sup> The studies of the Equal Opportunities Commission confirmed that the majority of carers are women (59 per cent) and that they receive little help generally from husbands, family or anyone else. "As long as they were prepared to continue without complaint other relatives and friends did not enquire too closely. When help was provided it was

usually from close relatives such as husbands.<sup>31</sup>

The Commission also reported discrimination against women carers in favour of elderly living alone and in favour of men carers by the domiciliary services including home helps and meals on wheels. There is a presumption that women can cope and that men cannot which is mediated by a set of expectations that it is appropriate for women to undertake a heavier burden of care than might be expected of men.

Since 60 per cent of women under retirement age are economically active in Britain the question of opportunity cost and wages foregone because of caring is an important one. Baldwin and Glendenning<sup>32</sup> examined it and found that, "severe disability in a child is associated with marked differences in women's participation rates, hours of work and earnings; and these disparities increase as the child gets older." Only 35 per cent of mothers of disabled children were economically active as compared with 59 per cent of mothers in the FES control group. They advocated greater flexibility for carers, male and female, who wish to combine work outside the home with the caring role.

Baldwin<sup>33</sup> did a further study of the extra financial costs to families who care for dependent children at home. This very detailed examination of day to day costs led her to conclude that the financial impact of the child's condition was considerable and pervasive. She advocated increases in benefits and an "expenses benefit" for carers

to offset the extra expenses invariably incurred.

Baldwin seems to favour a Fabian approach rather than a radical reformation of the system and this is what carers in her study seem to desire also. There remains, however, the conclusion of the Equal Opportunities Commission (1980), "It is socially unjust that those who perform the vital task of caring for the elderly should have to forfeit employment opportunities and employment rights to do so".<sup>34</sup>

Even leaving aside the problem of the costs borne by carers, the balance sheet of Community Care is uncertain. The issue of whether Community Care is necessarily less demanding on the public purse than residential care is complicated. There is no doubt that there has always been an assumption on the part of Governments that it is cheaper, certainly in the short run. There can be no doubting that it is more costly to look after an elderly person or handicapped child in a residential setting than it is when he/she is looked after at home without any help or support from social services. This is care by the community, informal care and "its hallmark", according to Webb and Wistow<sup>35</sup>, "is that it does not involve the State in expenditure - or is believed to involve only marginal expenditures." When it comes to care in the community, where the State is involved in expenditure on various services, the relative costs of such care and full-time residential care are difficult to estimate. This is true mainly because the State has never made adequate services available in the community in terms of personnel such as social workers, public health nurses, home helps

and paid volunteers. It is only when the State is prepared to put sufficient money into keeping frail elderly and mentally handicapped children in the community who have hitherto been forced into residential care that realistic comparisons can be made. One must face the costs of providing comparable levels of care in the community.

The Kent Community Project operated on two thirds of the cost of residential care for each frail elderly person it kept in the community. They survived on this sum and they even had a little to spare in the early years of the experiment. The most recent studies of the Project confirm continued success within the initial self-imposed financial constraints.<sup>36</sup> Perhaps this should be the target of Governments, but unfortunately when there have been cuts in public spending they have affected the Community Care side as much if not more than the residential. More often than not in the case of the elderly and the mentally handicapped, as Webb and Wistow<sup>37</sup> point out, "the parents are faced with the choice of placing their child in residential (or hospital) care or carrying on unsupported in the home."

Rimmer<sup>38</sup> argues that if the present philosophy of shifting the burden of care from the State back to the family continues, women will suffer disproportionately. She points out that most of the costs to the carer are never computed in the economics of Community Care. This would

involve what Abrams<sup>39</sup> described as a "language for translating psychological costs into cash terms". He believed that if such cost-benefit analysis could be done it would prove that Community Care would prove a great deal more expensive than residential care.

The social costs to the carer include emotional stress, physical fatigue, worry about the cared-for person and the future, curtailment of social life, strain on carers' marriages as well as interference with work outside the home. Bayley<sup>40</sup> documented many of these as early as 1973 and they have been confirmed in recent studies such as that of Nissel and Bonnerjea,<sup>41</sup> who describe how some women had to give up work with the loss of badly needed family income while others tended to combine work and caring which gave rise to patterns of arriving late and being worried all day about the elderly cared-for person. Glendenning<sup>42</sup> found a high incidence of loneliness and isolation among carers. The Equal Opportunities Commission (1982)<sup>43</sup> lists these social costs under the headings of emotional, social and effects on employment opportunities. These are set out in detail and they touch upon all the costs already mentioned with the addition of depression, strained family relationships especially between wife and husband, lack of money and lack of space to entertain friends.

While the costs to the carer are amply documented, the rewards to the carer have received considerably less mention in the literature. The balance, Vincent states,

is being restored. She points out that, while earlier literature tended to stress the costs of caring to individual women carers, the rewards are beginning to be recognised more in very recent times.<sup>44</sup> This is due she says to "feminist analyses of female roles and experiences". In the early literature the rewards rarely received any mention and tended to be viewed as the bait which lured the carer into the caring trap. For example, Baldwin and Glendenning:<sup>45</sup> "It would be wrong, however, to overlook the fact that the care of a dependent child has its own compensations and that many women with severely disabled children derive substantial rewards from this specialised task. These pleasures and satisfactions rooted in feelings of love and protectiveness are reinforced by "public opinion", and by ideological values attached to motherhood and the family by contemporary social welfare institutions and practices." Graham<sup>46</sup> warns that because of the separate analysis of caring as labour and love by sociologists and psychologists respectively, "its most distinctive and most compelling qualities have been lost". The rewards to caring are among the missing. The Equal Opportunities Commission<sup>47</sup> also mentioned the rewards: "Despite the social and economic restrictions experienced by carers, there is no doubt that for many people the emotional rewards of caring far outweigh the disadvantages. However, the existence of intangible advantages does not justify the continuation of policies which ignore the basic rights of women ...."

Considering the evidence on caring, one would not expect

writers to be "over the moon" about the rewards of caring, but I believe that the other side of the moon, in this case, the unexplored side of caring, needs to be examined even though it is invisible and "intangible" as the Report put it. Surely the rewards to the carer are one main reason why carers continue to bear such costs? I believe that when they are better understood and fully acknowledged without qualification we will be in a position to improve support services for carers.

So when recent writers such as Briggs and Oliver<sup>48</sup> describe it as "the claustrophobic atmosphere of twenty four hour a day servitude" which produces "a tinder-box of resentment, anger and rebellion" one is conscious that there may be another side to the story. For Graham<sup>49</sup> it is an "act of female sacrifice and supreme selflessness". The Equal Opportunities Commission<sup>50</sup> concluded its examination of the effects of caring upon the carer: "The rewards of caring are more likely to be forthcoming when the caring role is freely chosen by the carer, and she is welcomed by her charge ..."

A very important contribution to clarifying the concept of caring was made by Parker<sup>51</sup>. In a short space he did for "tending" what Bradshaw once did for "need". He identified four practical features: duration, intensity complexity and prognosis.

DURATION: how long the commitment is likely to last must be an important consideration for someone undertaking the caring task. People are naturally

cautious to commit themselves in an open-ended caring situation. In informal care, there are no fixed hours, no set times off.

INTENSITY: the degree of tending may vary from fixed tasks done once per week to being on all twenty four hours a day to feed, wash, lift and comfort, thus probably interrupting a whole range of other activities such as employment, leisure and education.

COMPLEXITY how far are special skills required? Caring can involve administering special diets, insulin injections, various medicines and coping with confusion and anger in a cared-for person. "Relationships with and around dependent people can become complicated even when the physical tasks are simple".

PROGNOSIS: Whether more or less care is likely to be required as time passes. Parker points out a difference between caring for young and old. In the case of the young a steady reduction in need can be expected while the elderly are likely to deteriorate progressively. "It is crucial to include the idea of prognosis", he concludes.

Parker's searching analysis of the concept of "tending" enables us to work out more systematically the dimensions of care which vary from one caring task to another. The degree of variation is enormous. For many caring is light but for a minority the burden can become unbearable. And the carers vary in age, health and in their motivation. Parker made explicit what must be the doubts and fears of

carers facing the caring task for the first time.

A number of practical experiments in Community Care have been set up and monitored. The best known is the Kent Community Care Project.<sup>52</sup> There is also the Gofal System<sup>53</sup> in North Wales, the patch-based community of Hadley<sup>54</sup> and a variety of good neighbour schemes described by Abrams.<sup>55</sup> These are all locally based service delivery systems which provide a more familiar and accessible service to the community than the formal social services normally do. In all the schemes "natural carers" are identified and supported.

The Kent Community Care project overcomes Parker's problems of "duration" by providing back-up care so that the carers of the frail elderly can take breaks at definite times. Contracts are drawn up with local people to do specific tasks. The elderly were all assessed as people requiring residential care before the experiment commenced. The Gofal System involves the same kind of contracts for similiar small financial payments. Another new feature of the Kent Community Care Project is that the social workers were given control over the budget. This is always a difficult bridge to cross between a Social Service Department or a County Council and social workers in the field. Administrators are always most reluctant to issue what is suspiciously like an "open cheque" to social workers who may lack the business acumen and fall for sob stories. The Kent experience was to illustrate

this: "Despite the decentralisation of the budget in terms of allocation it did not prove possible also to decentralise its distribution. Hence a considerable amount of time has been consumed in continuing negotiations with Central Office Treasurer's Department over the administration of contract payments." Such difficulties confirm Abrams' doubts about the existence of a continuum between formal and informal care. There are several bridges to be crossed between professional and lay people and between administrators and both of the other groups before understanding and trust can be established. The Kent Community Care Project seems to have negotiated the crossing successfully in the end.

The upper limit of two-thirds of the cost of corresponding care in a residential home to be spent on any individual client proved to be slightly more than was in fact necessary. But the Kent scheme has a further attraction. It shows clearly that while Community Care is not exactly welfare on the cheap, it is, nevertheless, cheap welfare when compared to the extra cost involved in comparable institutional care. It is at this price or somewhere near it that Community Care must be accepted as a "good buy" by Social Service Departments. Recent indications also confirm that the Kent Community Care Project has been successful in keeping elderly people in the community when they would otherwise have been in residential care.<sup>56</sup> Almost twice as many of the frail elderly in the Project sample were still at home after one year as in the

comparison group.

The Gofal Scheme, as described by Wenger,<sup>57</sup> showed how the community began to become involved as the contracted helpers began to be assisted by spouses, children and neighbours. Relatives who had held back lest they become trapped, now came forward when they found that they would not be on their own and left to do everything for the cared-for person.

Such controlled social experiments in Community Care have proved the value of formally assigning helpers manageable tasks which do not overwhelm or isolate them. The small payments are not meant to be more than an incentive, but obviously they count with the helpers and with their network. They prime the pump as it were. So Community Care has developed from the vague notion that everybody would be helping everybody, everywhere, at all times, to a manageable situation in which specific people perform well-defined tasks for frail elderly, at set times and for a small payment. Much of the vagueness is banished and with it go doubts and fears.

Before leaving the practical experiments in Community Care, and they are a growing phenomenon both in the U.K. and in the U.S.A.<sup>58</sup> I should like to include an experiment of a different kind. This is the Jean Vanier<sup>59</sup> Community, L'Arche, where small groups of handicapped people are befriended by "assistants" who are largely unpaid or

underpaid and who enter into a relationship of friendship with the handicapped. As Parker noted, "tending beyond the superficial level, is likely to establish close relationships, affection and a sense of obligation. These are not easily abandoned." Vanier and his assistants set out deliberately to foster the growth of the handicapped through developing personal relationships of friendship and through sharing a common life. Work, meals, prayer and recreation are in common. Relations with the local community are fostered to counteract prejudice against the handicapped. Being with the handicapped is more important than doing things for them according to Vanier. His work is based on profound respect for the dignity and potential of the handicapped who have their own particular gifts - gifts of the heart mostly, though not exclusively when one considers handicapped people like Christopher Nolan. The assistants find that they learn a good deal from their contact with the handicapped and, not least, they learn about themselves and their "brokenness", as Vanier describes their own needs for friendship and search for meaning in their lives. The idiom in Vanier is very different from much of the literature which describes caring as a "burden", "a daily grind", "a bleak form of servitude". According to Vanier, the carer also grows through the experience in the Community. There is a two-way process of enrichment. The handicapped are not written off as useless, the assistants are assumed to have their emotional and social needs too. Describing his personal experience in the first months after he

went to live with two mentally handicapped men near Paris in 1964, Vanier says: "I had to learn that L'Arche was not just my project but also Raphael's and Philippe's and that many others were to come to L'Arche and put down roots there. I had to discover something about welcome and respect for people, something about liberation of hearts and patience. I had much to learn about myself and my faults and defects, my need to dominate and command after spending eight years in the Navy. I had to learn about human growth and suffering, about sharing and about the ways of God."<sup>60</sup>

Other accounts<sup>61</sup> agree that these communities, whose only therapy is "family living together, where we share, work and pray, suffer and celebrate together, where we grow together in love, in hope and in freedom of heart" are happy. Such a project involves the risk which people take when they "venture out from behind their frontiers and meet others, discover their beauty and learn from them." "Is this a dream or Utopia?", asks Vanier. The context is that of close relationships, of belonging. It involves reciprocity, giving and receiving. It involves self-sacrifice. But if its costs are high, so are its rewards. "So the Community takes on a wider meaning. It is lived not only among its own members but in the larger community of its neighbourhood, with the poor and with all those who want to share its hope. So it becomes a place of reconciliation and forgiveness where each person feels carried by others and carries them. It is a place of

friendship among those who know that they are weak but know that they are loved and forgiven. Thus community is a place of celebration.<sup>62</sup>

Such descriptions of care in the community would seem far-fetched were it not for the fact that they are working well in a variety of countries including France, England, Belgium, Canada, Ireland, Denmark, India, Haiti, Honduras. While it is clear that such living demands a degree of commitment not easily given by the ordinary person, it does highlight a vital dimension of caring which seems to go largely unnoticed in other literature: that of service and sharing within a moral community as a genuinely self-selected life-style. Vanier's own life could be truly described as an act of male sacrifice and supreme selflessness.

But to return to the main literature, the concept of Community Care has been gradually developed and clarified over the past thirty years. The practical experiments at local level have given promising results, initially at least. The problem has been that Governments have never been willing to commit the level of finance which would permit the successful growth of Community Care.

The recent work of Dalley<sup>63</sup> rounds off this literature review in an intriguing manner. She calls for a return to "collective care". She reacts against the family and the "familist ideology" in much the same way as

the proponents of Community Care reacted against Poor Law institutions in the post World War 11 days. Family care of elderly and handicapped, Dalley claims, "is much favoured by Governments as a money saving device and it depends on 'compulsory altruism' on the part of women." Women are forced by the prevailing ideology of familism to sacrifice themselves as unpaid carers. This is bad for the carers and bad for the cared-for. Dalley invokes Titmuss and the "*Gift Relationship*" which demonstrated that, "for the gift to be safe, that is non injurious to the recipient, it had to be freely given."<sup>64</sup>

So Dalley proposes a socialist alternative to community/family care which divides the burden of caring across the whole of society. Caring would be shared by family, neighbours, local community and social services in a flexible manner. The family itself would have to admit the collective spirit and join with outside groups of families in communal facilities where dependents could be cared for in company with others and in solidarity, in the place of the often isolated and lonely setting of the nuclear family where carer and cared-for are thrown together. This collective provision would relieve carers from much of the strain experienced at present. It would also make for better relations and a higher standard of care for the cared-for. Dalley surveys many forms of collectivism in different societies and in different eras of history. She eschews the stigma

of the Poor Law institutions on the one hand but on the other she warns that we must "beware of domesticity".<sup>65</sup> Consequently, child care, housework and the care of the elderly and handicapped should be socialised. "The feminist alternative", Dalley concludes<sup>66</sup> "is of a society which willingly takes a collective responsibility for all its members, which values the activities of caring and recognises the worth both of those cared for and those doing the caring. It sees collective responsibility as essentially non-gendered, entering every level and every domain. 'Unpaid', 'voluntary' or 'informal' care is not given a higher moral value than care provided by the collectivity - such care is too often the outcome of compulsory altruism and is exploitative of both giver and receiver."

The review of the literature might lead one to conclude that there are fashions in Social Administration, that institutions are out in one era and back in again in the next ! This would be quite unfair to a discipline which has never gone in for colourful outward shows ! What has occurred is a development in our understanding of Community Care as changes in society and in the family forced us to clarify the concept. Secondly, while social research in the sixties and seventies focussed almost exclusively on the cared-for, more recent studies have focussed on the carers thus giving us a new perspective. The feminist movement has introduced a new and challenging ideological element to

the debate on Community Care.

However, one important question has not been answered in the literature to date. Given the high costs to carers, why do they continue with their task? The literature on costs must clearly predict that care by the community, i.e., care within the family, by the woman usually, must be in rapid decline. Yet the fact remains that the vast majority of frail elderly and mentally handicapped are cared for outside of institutions. The family is proving itself to be an extremely resilient caring agent. How are we to account for this?

Perhaps, there is another side to the balance sheet? Perhaps there is a benefits or rewards side which makes up for the costs in whole or in part? The durability of care could in theory be accounted for in three ways:

- (a) Carers have a sense of duty which stems from family, moral or religious values;
- (b) Carers experience rewards for caring which make up for the costs or even outweigh them. There is a trade-off, conscious or unconscious, on the lines of the calculus mentioned by Abrams who stressed repeatedly that reciprocity was the main motivation in Community Care;
- (c) Self-sacrifice, frequently mentioned in the feminist literature, is the driving force. Self-sacrifice transcends duty and rewards. It is a "hot" concept while duty is a "cold" one.

In the end carers will probably express it  
in terms of love.

I shall address these questions in the final chapters and I should hope to throw new light on the dynamics of caring. Do carers stay at their posts because of a sense of duty or because of rewards experienced or again because they undertake it in a spirit of self-sacrifice? If all three factors are at work what weighting is to be given to each? A satisfactory answer to these questions would fill a present gap in the literature to date and would make an original contribution to Social Administration. One gap in the British literature, in particular, would be filled and this is the failure to date to properly document the rewards to the carer and to accord them their true weight in accounting for the durability of care. A second gap will be filled in the Irish literature by a study on carers which breaks new ground in relation to the mentally handicapped and where the first study on the carers of the frail elderly by the National Council for the Aged is still incomplete.<sup>67</sup>

The formidable task for academics and social policy makers is to create the public demand for a Community Care system which actively mobilises, organises and supervises formal and informal systems, and commits the necessary finance to it. Public demand for such an operation might then register with the politicians of a future Government. The economics of Community Care

should also commend themselves to any Government which looks beyond the short-run. It will cost money but it will be cheaper in the long-run than residential care. One is seeking to build up the political will for as big a break-through as the Labour Government achieved in setting up the N.H.S. in the years after World War 11. Now what is needed is an option for Community Care on its economic and social merits rather than by way of a reaction to Poor Law institutions. Then, and not till then will Titmuss' "cottage garden trailer" come to flower !

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## CHAPTER 4

### METHODS

The previous study on Loneliness played a crucial role in my approach to the present study. In the Loneliness study I had cocked a giant ear at the needs of the elderly in the Kerry Diocese. I was alerted to the problems of the sub-group of over 75s, who generally lived with relatives and reported more loneliness and boredom than those who lived alone.<sup>1</sup> Incapacity was the important factor here. Infirmity increased with age and the inability to take an active part in the social life of the area caused much unhappiness.

My attention began to be directed to the caring relatives who were frequently spouses or siblings. But it was only very gradually that I realised that these caring relatives, whatever their age, could be under many pressures resulting from their caring task.

This thorough investigation gave me a feel for this age group and was a most interesting comparative study for me since I had studied the work of Shanas<sup>2</sup>, Townsend and Wedderburn<sup>3</sup>, Hadley and Webb<sup>4</sup>, Tunstall<sup>5</sup> and later Wenger<sup>6</sup>, Power<sup>7</sup>, and Kivett<sup>8</sup> on loneliness among the elderly in England, U.S.A., Denmark, Wales and Ireland. It also served, in effect, as a pilot study in the context of the present study of carers. A pilot study of 474 hour and a half long interviews must be somewhat

unusual in this field ! But it did mean that the present study was carried out against an empirical background on the lives of the elderly in the area in which I had grown up and worked as a priest for twenty years.

The two interviewers used in the loneliness study, both young women, were students of mine in their final year of their degree course at University College Cork and this project formed part of their fieldwork training. The work we undertook together demonstrated that 35 per cent of the sample felt themselves to be lonely sometimes. Of this 35 per cent, 15 per cent said they were lonely always or often. 70 per cent thought that loneliness was a problem in the country generally and 60 per cent thought that there were a lot of lonely people in their own area. 56 per cent felt that some of their neighbours suffered from loneliness. Cross-tabulation showed a direct and significant relationship between attribution to others and eventual admission of ones own loneliness. The questions were the standard ones used in the literature up to then. They were strategically placed about half way in the interview after more general questions had been broached and rapport established.

More recent writers such as Wenger<sup>9</sup> have questioned the use of the standard questions on the grounds that they rely totally on self reporting, that the subject carries stigma and therefore is unlikely to be admitted in all cases. Spouses, for example, might feel compelled to

deny this feeling lest they be disloyal to one another. Wenger<sup>10</sup>, though using the standard questions for comparative purposes, has designed a set of eight indirect questions on whether the persons felt they had sufficient companionship, whether they had people in whom they could confide and call on in a crisis and so on. In fact, Wenger found a higher incidence in this aggregate score than she did on the standard questions. She found that married women reported a good deal of loneliness, a finding which had not come up before in the studies. Wenger also wondered just what being "lonely sometimes" amounted to. After all we would all, if we were honest, have to say that we are sometimes lonely.

Granted the validity of many of her points, it must be said that while there may be a tendency to underreport in some cases, there may also be a tendency to over-report: for example, in cases of bereavement where it would be disloyal to the departed spouse not to admit to loneliness. To this must be added the possible interview bias of interviewers in search of loneliness and worried lest they come back to their Director empty-handed.

What comes through from internal examination of the results of the Kerry Diocesan Study was that the group that declared that they were "lonely sometimes" were wholly consistent in their responses to a whole range of questions on issues of companionship, the desire to see a visiting service set up, their attitude to death

and their actual participation in work and the social life of their communities. When asked if they would like more company, 51 per cent of the total sample said they would, 66 per cent of those who said they were "sometimes lonely" said "yes" and 91 per cent of those "always/often lonely" said "yes". A 75 per cent overlap occurred between those who were "sometimes lonely" and those who declared they were "often bored". Boredom certainly carries no social stigma since three year olds in the modern world frequently profess to be overwhelmed by it ! 36 per cent of the sample were "often bored", 75 per cent of the lonely were bored. And 75 per cent of those who were often bored were lonely.

The comparison of the different studies is reported in Table 4.1. It should be kept in mind that there were some variations in the actual wording of the standard questions on loneliness. Also, Hadley and Webb's sample were referred to as very frail elderly in the first place and thus more likely to suffer from loneliness and Power's sample all lived alone. Power's study, done on behalf of the St. Vincent de Paul Society, involved interviews done in Northern Ireland and in the Republic, a very rare achievement since the "troubles" began in 1969.

TABLE 4.1.

% Lonely		Always/ Often	Some- times	Never/ Rarely	Total lonely
Denmark: Shanas et al.	1968	4	13	83	17
U.K.: Shanas, Townsend et al.	1968	7	21	72	28
U.S.A.: Shanas et al.	1968	9	21	70	30
U.K.: Tunstall, Four Areas	1966	9	25	66	34
U.K.: Hadley & Webb	1975	29	42	29	71
Ireland: North and South, Power	1979	14	25	66	39
North Wales: Wenger et al.	1980	5	20	75	25
U.S.A. Rural: Kivett	1979	16	42	43	58
Ireland, Kerry Diocese: Clifford	1977	15	20	65	35

When Townsend tried to account for the difference between Denmark on the one hand and the U.K. and the U.S.A. on the other he described how a more private and formal pattern of relationships existed in Denmark than in other countries. The Danish old people had less need of friendship and had been more independent in their lifestyle throughout their lives. He concluded that the difference between them and the other two nations in the study was one of "emphasis" rather than of "kind".<sup>11</sup> The comparative studies are intriguing for the social scientist but I cannot delay any further over them here.

The second important finding in this study was the association between loneliness and physical incapacity.

The more incapacitated the person, the more likely he/she was to be lonely. It was striking. Incapacity was measured on the Townsend Wedderburn<sup>12</sup> and Sainsbury<sup>13</sup> model of a set of activities value-judged to be central to normal living for elderly people in modern society. These can be classified as "personal" and "household" tasks. From 2.5 per cent to 4 per cent found great difficulty with personal tasks but the degree of difficulty rose with the more complicated household tasks such as cooking, bringing in fuel, washing clothes etc. where the numbers in difficulty rose to 25 per cent. Loneliness and the degree of incapacity were very closely related. The greater the degree of incapacity the more likely the old person was to be lonely. For example, among those who found "no difficulty" in dressing 30 per cent were lonely, of those who experienced "some difficulty" 72 per cent were lonely and where "great difficulty" was experienced 100 per cent were lonely.

This led me to the conclusion that there was a small sub-group of frail elderly whose physical and social needs were far greater than the general body, who by and large enjoyed a degree of independence and integration above what I had expected from the British and American literature. Of course, much of the literature in the 1960s and the early 1970s was inclined to dwell on the minority of elderly who suffered from extreme mental and emotional deprivation and the image of the elderly tended to be based on those in long-stay institutions

of the "Last Refuge" kind. The balance has been restored in the last five or six years with most writers beginning with a strong rejection of the earlier stereotype.<sup>14</sup>

#### THE SAMPLING METHOD

For the purpose of the present study I needed to find a sample of elderly people who were very likely to be frail and housebound and therefore likely to be dependent on carers to a considerable degree. The use of Baptism registers as in the Loneliness study would have yielded too few people of this kind for the present purposes. An alternative approach had to be found. The one actually adopted was almost certainly unique in the history of Social Science and could only have been relied upon in a country like Ireland where religious practice is exceptionally high. The sample was drawn from the list used by priests in their first Friday Communion calls to the housebound elderly because this proved to be the best guide to the frail elderly.

This method had the added advantage of enabling me to identify a sample of people who had not self-selected themselves as being in a special need or difficulty. So, therefore, it seemed reasonable to assume that this approach would enable us to identify "normal" carers rather than those who were under pressure and had

communicated this to one of the agencies. Recent studies such as that of Ungerson<sup>15</sup> selected twenty one carers from lists supplied by the Social Service Department of carers who had contacted them and Lewis and Meredith's<sup>16</sup> sample was to some extent self-selected. The forty one respondents in the latter were located "via the National Council for Carers and their Elderly Dependents, the Association of Carers, a letter to a local newspaper, a Social Services Department of a London borough, the manager of a Part 111 home, a hospital carers' support group and by personal contact". Ungerson<sup>17</sup> summed it up neatly: "Carers are notoriously difficult to find".

In the study on Loneliness, the two most regular official visitors to the homes of the elderly were the priest and the public health nurse. The social workers work almost exclusively with families and in child care. The priest visited 15 per cent at least once per month, while the public health nurse visited 9 per cent of them at least once per month.

The priest's monthly visit to the elderly is known as the First Friday Communion Call, a pastoral practice dating back to the early part of this century and universal throughout Ireland. The Irish have been traditionally very faithful to Sunday Mass at which attendance is obligatory unless illness or incapacity or other serious difficulties prevent it. In practice, according to

research done by the Church itself<sup>19</sup> and by Irish Marketing Research, the over-all attendance is approximately 90 per cent. Among the older rural people (51+) it ran as high as 95 per cent. When health and mobility decline beyond a certain point, the old person drops out and either he/she or the family inform the priest and thenceforth the priest comes on the first Friday of each month with Holy Communion. Ceasing to attend Sunday Mass is a land-mark in the old person's life and most are reluctant to surrender to what must be the final phase of life. Even among the most incapacitated group in the Loneliness study, 14 per cent had attended Mass the Sunday previous to the interview.

It therefore seemed to me to be a reasonable assumption that a further study involving the frail elderly might find its most reliable sample from the First Friday lists of the priests. The Church of Ireland ministers were invited to send names from their congregation but only a very small number of names were submitted. It is possible, of course, that a small number of elderly have lapsed and such people would have been missed out by this sampling method. I believe that their number would be very small indeed. They would however be very likely to be isolated or lonely.

(see Sainsbury S., reference 13)

When incapacity was measured on a scale (from 0 to 14 on the list of personal and household tasks, it was found that the priest's visit increased with the degree of

severity. The monthly First Friday call stands out.

TABLE 4.2. INCAPACITY AND PRIEST'S VISITS

%	Percentage receiving visits:					
	Weekly	Monthly	Few Times per year	Yearly	Never	N.A.
0 Score	0.3	4.8	4.8	3.8	80.8	5.4
1-7 Score	0.0	13.8	8.0	5.7	70.1	2.3
8-14 Score	2.8	40.3	8.3	8.3	40.3	0.0
(n = 474 )						

The other alternative would have been the public health nurses visiting lists, but since the public health nurse was to be "investigated" this seemed inappropriate. As well, it seems pretty certain that there are not enough public health nurses in many areas as the ratio of nurses to population is lower in the Southern Health Board, where this study was done, than in any of the other seven regions. The public health nurse is thought to visit 2-3 per cent of the elderly in this country as a whole as mentioned earlier.

The General Practitioner might have been called upon but issues of confidentiality would inevitably arise. I believe also that social scientists must have faith in the measuring tools of their own discipline for all its "vaguearies" and value judgements. It seems also that many of the elderly only send for a doctor in crisis situations so that doctors may know little enough about

individuals. There was, of course, the carer, who is the best informed person on the health and well-being of the cared-for person. The carers could be presumed to have what Webb and Hobdell<sup>20</sup> described as the "authority of relevance" in the case of their charges.

A harmless enough question appeared at the extreme right-hand margin of the question on incapacity in the Loneliness study. It asked those who had "great difficulty" or those who "had to be helped" with personal or household tasks, "If you can't, who helps?" Like Richard Titmuss' social services and the train journey, this marginal question turned out to be part of the journey, or of the next journey at any rate. What seemed to be a side issue then, i.e., the caring person, was to become the subject of my next study. What seems very strange ten years on is the fact that the responses were coded as "spouse", "child" etc. without a mention of the sex, let alone gender, of the carers! Moroney<sup>21</sup> who was writing around the same time has been taken to task recently by Ungerson<sup>22</sup> for referring throughout his book to "family care" and never to "woman care" and was described as "implicitly extremely anti-feminist". Table 4.3 below names the sources from which help was received.

TABLE 4.3. SOURCES OF HELP FOR INCAPACITATED ELDERLY  
IN LONELINESS STUDY

( n = 474 )  
( % )

Person who helps when task cannot be performed:	Spouse	Child	Other Relative	Neighbour	Volunteer, Voluntary Organiz- ation
Dressing	0.2	-	-	-	-
Washing	0.4	0.2	-	-	-
Making cup of tea	0.8	1.3	0.6	0.2	-
Cooking a hot meal	4.0	4.0	1.5	0.6	1.3
Doing light house- work	5.7	5.9	2.1	0.8	0.6
Doing heavy house- work	7.0	10.1	2.5	1.7	0.4
Washing clothes	9.3	10.8	2.8	1.9	0.8
Carrying in turf/ coal	1.9	12.0	2.8	1.9	0.2

As stated earlier, the sample of elderly were selected from First Friday lists submitted by 50 priests from 18 parishes chosen at random from the 54 parishes of the Diocese. Two Church of Ireland ministers submitted five names. The priests were asked to state, if possible, whom they considered to be the main caring person. In this they were not always very precise nor was it possible to be in some cases. But the involvement of priests made it possible to seek further information in doubtful situations.

A total of 1170 names were put in alphabetical order and one in nine names was selected by random choice. Of this 130, eleven had died in the twelve months between

selection and the interview, two had gone to a residential home, one to a long stay hospital and three refused to acknowledge that they had any carer. There were no refusals on the part of carers where they could be identified. In all, 119 interviews were done but 6 were not valid either because the cared-for person had died or gone to a residential home. It was decided to interview those for general interest and a few of them are mentioned later on in the study. It is interesting to find that Lewis and Meredith<sup>23</sup> did their study on carers who had ceased to care for some time and built up "caring biographies" of daughters who had cared for mothers.

The sample of handicapped was drawn from a list compiled with the help of the Director of Community Care and it included all the moderately and severely handicapped and those on the waiting list of St. Mary of the Angels, those in the residential and day schools and those in the two Training Centres. Since I was known personally to most of the children and young adults and to their parents, I had no difficulty in gaining access. There were no refusals. In fact, the carers welcomed the opportunity to talk about their experiences and their problems. A total of 86 interviews were completed with the carers of the mentally handicapped. Altogether, there were 205 interviews ranging from one and a half hours to three hours in length. Of the 205, six were not included in the analysis as mentioned earlier.

One of the problems encountered was that a small number of the elderly when approached said that they did not have a carer. They insisted on their independence and said they needed no assistance. One man aged eighty four said he kept a gun in case of night attack, another said that "nobody looks after me except Almighty God". A third aged eighty two on whom I called in his pub took offence at the very suggestion that he needed a carer. "Do I look decrepid?", he asked. His son and daughter lived in England and phoned him regularly. When I gained his confidence after buying and drinking three orange juices he confessed that he had a paid home help. At the end of our meeting he asked if I could use some influence to have the home help paid by the Health Board! Three of the sample were ruled out when they claimed to have no carer and these included the independent publican! Otherwise, the elderly very readily identified their carer who was contacted and interviewed. Occasionally, it was not easy to decide who the real carer was. For example, an 86 year old man who was crippled with arthritis had a son who lived with him in the home and a married daughter who lived a mile away. The son worked at night in a factory and naturally spend most of the day in bed. The daughter came and cleaned the house and got the old man's meals. The daughter was the one chosen as the carer.

## THE QUESTIONNAIRE AND THE INTERVIEWING

After the usual background information, a short life-history was strategically placed in the questionnaire. The "life history" technique was suggested to me by Malcolm Johnson<sup>24</sup> when I called on him prior to designing the questionnaire. His idea was to give the interviewees full freedom to outline their life stories in their own way. The main events as seen by the individual can be far more relevant than the structured sets of questions usually administered by interviewers with regular schedules. Johnson would make the life history the major part of the interview with a few starter questions at the beginning and some prompting along the way. I decided to include a shortened version, to limit the life history to that part relevant to the caring task, e.g., the mother's story from the birth of her handicapped child, the moment she discovered that the child was handicapped and her experiences since then. Or, in the case of a carer of the elderly, how the caring task was initially entrusted to her and the story since then. This technique yielded rich rewards as individuals willingly told their stories with feeling and vivid memories. Not all the interviewers were equally successful in getting the carers "to talk", but overall, this question added a unique dimension to this study. I feel that this was a very worthwhile question and it seemed also to open up the interview as it established rapport. More than one third of these "life histories" are

reproduced without alteration in Appendix 1.

The questionnaire went on to examine the degree of help needed by the cared-for person and the actual "daily grind" of caring. Then the actual help received from others was examined, that of spouse, children, neighbours, friends, social services and voluntary bodies. Further sections dealt with the motives for caring, the joys and sorrows, costs and rewards as the carer saw them. Some questions were asked about the State welfare payments received and about the carer's attitude to employment outside the home. The question of the carer's leisure activities, holidays and breaks was examined. The cultural expectation that caring is more appropriately a woman's role than a man's role was gone into in different ways. At the end the interviewer was asked to comment on the carer and on whether it was likely that the caring would be continued. The questionnaire is reproduced in Appendix 2.

I included two vignettes in the questionnaire. I had used this technique in a previous study on social stigma<sup>25</sup> and found it useful as a method of eliciting sensitive information. Respondents showed considerable powers of problem solving and in the process revealed personal feelings which would be difficult to tap through direct questions. I felt that this tool ought not be

omitted on this occasion although I used it sparingly.

The two vignettes went as follows:

(i) (Ask women)

Suppose a good friend of yours came to you with this problem. She has a job as a secretary in an office in town, but now her mother has got a stroke and needs continual care for the foreseeable future. Should she give up her job and mind her mother? Or should she seek some other way out? How would you advise her in her dilemma?

(ii) (Ask men)

Suppose a good friend of yours came for advice. His mother has had a stroke and needs continual care for the foreseeable future. He works in a drapery shop. Should he give up his job and mind his mother? Or should he seek some other way out? How would you advise your friend in his dilemma?

The study was funded from my salary with the exception of £3000 realised in a concert for the elderly of the Diocese. The performers gave their service free of charge and the younger generation provided transport for the elderly. The total cost of the study which included paying the interviewers and the E.S.R.I. for computerising the results was approximately £8000.

The research involved a great deal of travelling in this sparsely populated area. The interview team consisted of two ladies in County Kerry recommended by the Economic and Social Research Institute because of their previous participation in market research for the Institute. I also had the services of a third lady, an honours graduate from U.C.C., who has worked on my previous studies, a priest who is chaplain to Killarney Psychiatric Hospital, St. Finian's, and trained in Marriage Counselling and interviewing, and I did some interviewing myself.

I directed this team and discussed the finished schedules with them as they went along. The E.S.R.I. interviewers were extremely accurate in recording answers to all questions but needed much tuition in the life history technique with which they were unaccustomed. However, this aspect improved and their initial weaknesses in this area were compensated for by the strength of others in the team.

The participation of priests as interviewers in this study gives rise to the question of whether the carers might have responded differently to lay interviewers than they did to priests. In fact, the priests did 26 interviews out of the 205 and all their interviews were with carers of the elderly. It is possible that on certain questions the carers might answer to please the priest and that they might be loathe to express their dislike of the caring task knowing the Church's teaching on duty to parents for example. On the other hand, it could be argued, the priest is one in whom people trust with confidential information, so perhaps, they would confide more in him than in lay interviewers. Cross-tabulation on a large number of issues where bias might be expected, showed that there was no significant difference between attitudes of carers as expressed to priests and to lay interviewers on almost all issues. For example, there was no significant difference on the question as to whether the carer felt a sense of duty to look after the cared-for person; nor on whether

preparing the house for the priest's first Friday visit caused extra work for the carer. The same applied to the question about caring placing a strain on the carer's marriage and on the question of regret on the carer's part that she was not in full-time work. However on reporting on disagreements with the cared-for person, the carers were more likely to admit their loss of temper to the lay interviewers than to the priest ( $s = .02$ ). But on the question as to whether religion or family was the greater source of their sense of duty there was no significant difference between responses to priest and lay interviewer.

At the end of the day, I felt very happy to have done this original work, a comparative study of carers of two groups, the frail elderly and the mentally handicapped, in an Irish setting. It was also the logical conclusion to previous studies and fitted in well with my pastoral experience. Just when the interviews were being completed, I was promoted and had to bid farewell to Kerry.

NOTES

1. Clifford, D., 1977, *"The Kerry Diocesan Study on Loneliness"*, Unpublished

Loneliness and Family Integration

<u>Living with:</u>	<u>% Lonely</u>	<u>Living with:</u>	<u>% Lonely</u>
Spouse & children	12.0	One child only	45.2
Spouse & one child	16.8	Non relatives	50.0
Spouse only	17.5	Brother or sister	55.8
Two or more children	33.0	Living alone	58.4
Male child & his nuclear family	34.4	Living with other relatives	60.01
( n = 474    s = .0000 )			

2. Shanas, E., Townsend, P., Wedderburn, D., Friis, H., Milhij, P., Stehouwer, J., 1968, *"Old People in Three Industrial Societies"*, Routledge and Kegan Paul, London
3. Townsend, P., and Wedderburn, D., 1965, *"The Aged in the Welfare State"*, G. Bell & Sons Ltd., London
4. Hadley, R., Webb, A.L., and Farrell, C., 1975, *"Across the Generations"*, George Allen and Unwin, London
5. Tunstall, J., 1966, *"Old and Alone"*, Routledge and Kegan Paul, London
6. Wenger, G.C., 1984, *"The Supportive Network"*, George Allen and Unwin, London
7. Power, B., 1979, *"Old and Alone in Ireland"*, St. Vincent de Paul Society, Dublin
8. Kivett, V.R., "Discriminators of loneliness among rural elderly: implications for intervention", *The Gerontologist*, Vol.19 No.1 pp. 108 - 115
9. Wenger, G.C., 1985, "Loneliness: A pattern of measurement", *Unpublished paper*
10. Wenger, G.C., 1981, "The Elderly in the Community: family contacts, social integration and community involvement", Working Paper No.18, *Social Services in Rural Areas Research Project*, University of North Wales, Bangor
11. Townsend, P., in Shanas et al., op.cit. p.271

12. Townsend, P., and Wedderburn, D., op.cit. Ch.1
13. Sainsbury, S., 1970, *"Registered as Disabled"*, George Bell & Sons, London
14. See Wenger, G.C., (1984), op.cit.Ch.1 or Pyke, M., (1980), in *"Long Life"*, J. M. Dent & Sons Ltd., London.  
 Wenger states:  
 "When we hear about old people we are usually told about their difficulties. This is because most research has focussed on the problems of the elderly. This book is different in that it takes as its subject retired people living in their own homes in the community and for the most part coping capably... it hopes to challenge the negative stereotype of old age...."  
 Magnus Pyke gives a highly sympathetic and personal account of the positive aspects to being old in to-day's world. He states:  
 "In 1975, a large group of elderly people living in their own homes was studied in Scotland. It was found that the percentage needing some help in living a normal life was about a quarter of those aged between seventy and seventy four and about a third of those between eighty and eighty four. At the age of eighty five and over, most of them required support of one kind or another. Yet even so, three quarters of the over eighty fives - after twenty and twenty five years beyond the accepted age of retirement - retained their ability to cope with the ordinary affairs of daily life provided they had appropriate help." (Ch. 2 p.17 )
15. Ungerson, C., 1987, *"Policy is Personal"*, Tavistock Publications, London
16. Lewis, J., and Meredith, B., 1988, *"Daughters who Care"*, Routledge, London,
17. Ungerson, C., 1987, op.cit.
18. Clifford, D., November 1986, "The First Friday Communion Call", *The Furrow*, Vol.37 No.11
19. *A Survey of Religious Practice Attitudes and Beliefs in the Republic of Ireland*, Research and Development Unit, Maynooth, Ireland, 1976

See also: *Religious Beliefs Practice and Moral Attitudes: A comparison of two Irish Surveys 1974 - 1984*, Research and Development Unit, Maynooth, 1986

Mass attendance in Rural Ireland was 94.2 per cent in 1974 and 93.6 per cent in 1984. The corresponding urban figures were 86.0 and 76.7 respectively.

Overall attendance in 1974 was 90.9 and 86.9 per cent in 1984. Among the oldest group (51+) the figures remained at 92 per cent for both urban and rural over the ten years. The fall off has taken place in urban areas and among the young age group (18-25)

20. Webb, A.L., and Hobdell, M., 1980, in Lonsdale, S., Webb, A.L., and Briggs, T., (eds.), *"Teamwork in the Personal Social Services"*, Crown Helm
21. Moroney, R.M., 1976, *"The Family and the State: Considerations for Social Policy"*, Longman, London.
22. Ungerson, C., 1987, op.cit.
23. Lewis, J., and Meredith, B., 1988, op. cit.
24. Johnson, M., 1981, "Ageing Needs and Nutrition", Interview Document, Policy Studies Institute, London also  
"Observations on the Enterprise of Ageing", *"Ageing and Society*, Vol.2 P.1, March 1982, Cambridge University Press
25. Clifford, D., 1975 (a), "Stigma and the Perception of Social Security Services", *Policy and Politics*, Vol.3 No.3

## CHAPTER 5

### THE CARERS : BASIC DATA

In the case of the mentally handicapped, the carers were almost all women (97.7 per cent). In the case of the elderly, 72.6 per cent were women. The 27.4 per cent men who were carers of the elderly formed a lower proportion than those of the Equal Opportunities Study (1982)<sup>1</sup> where 41 per cent of the carers were male.

#### AGE OF CARERS

The age of the carers, as may be expected, was <sup>not</sup> significantly different between the two groups in this study ( $s = 0.38$ )

This can be seen from Table 5.1.

TABLE 5.1.

#### AGE OF CARERS

Age of Carers	Carers of Elderly %	Carers of Mentally Handicapped %
Under 30	4.5	6.0
30 - 35	13.3	13.0
35 - 50	38.2	56.6
50 - 65	28.6	32.7
65 - 75	17.9	3.6
75+	3.0	1.2

One has to be careful not to stereotype the carers any more than the elderly, as mentioned earlier, since their age span is also wide. One is less surprised by this

age spread of the carers of the elderly who will naturally include many spouses and siblings as carers, but the ages of the carers of the handicapped is somewhat surprising and has some implications which will be mentioned later. Of course, when one remembers that some adult handicapped were included from Workshops and Training Centres this finding is not quite so unexpected. 25 per cent of the handicapped are over 18.

#### OCCUPATION

The occupations of the carers were in the main given as "housewife". For the carers of the handicapped this was the case for 91.9 per cent as against 55.7 per cent for the carers of the elderly. This reflects the high level of unemployment in the area generally as well as the kind of caring for elderly or handicapped and other children very often. In the towns, some part-time work exists for such jobs as waitresses in the hotels especially in tourist areas. But in the country, jobs are generally very scarce.

TABLE 5.2. OCCUPATION OF CARERS

Occupation	% ( n = 192 )			
	Carers of Elderly	Carers of Handicapped	Male	Female
Housewife	55.7	91.9	0.0	73.0
Farmer	12.3	1.2	44.4	1.3
Retired	10.4	1.2	25.9	5.1
Unskilled manual	5.4	-	7.4	5.1
Skilled manual	3.8	1.2	-	-
Intermediate non-manual	6.6	-	-	-
Lower professional	2.8	1.2	-	-
Higher professional	0.8	3.5	-	-

The participation of female carers in work outside the home is very small indeed. The question of their previous participation and their attitude to work outside the home will be discussed in more detail later.

#### MARITAL STATUS

The two groups of carers differed significantly<sup>2</sup> in relation to marital status, the great majority of the carers of the handicapped being married as will be seen from Table 5.3.

TABLE 5.3. MARITAL STATUS OF CARERS

% ( n = 119 )	MARITAL STATUS OF CARERS			
	Carers of Elderly	Carers of Handicapped	Male	Female
Married	61.9	84.9	41.9	69.5
Single	31.0	2.3	51.6	23.2
Widowed	5.3	9.3	3.2	6.1
Separated	1.8	3.5	3.2	1.2

RELATIONSHIP WITH CARED-FOR-PERSON

The carers of the mentally handicapped are much less varied than those of the elderly in regard to their relationship with the cared-for person. The huge majority are mothers looking after their offspring. Table 5.4 shows the pattern of the relationships which are almost completely blood relationships apart from one relationship by marriage and one foster parent-child relationship.

TABLE 5.4.      RELATIONSHIP BETWEEN CARER AND CARED-FOR  
HANDICAPPED GROUP

( n = 86 )

CARER	CARED-FOR HANDICAPPED	%
Mother	Son	52.3
Mother	Daughter	41.8
Mother	Foster daughter	1.2
Father	Daughter	1.2
Sister	Brother	1.2
Sister-in-law	Brother-in-law	1.2

The elderly and their carers contained a much wider variety of relationships including blood, marriage and relationships of friendship and neighbourliness.

TABLE 5.5.      RELATIONSHIP BETWEEN CARER AND CARED-FOR ELDERLY

CARER	CARED-FOR ELDERLY	%	NUMBER
Daughter	Mother	16.5	19
Son	Mother	7.8	9
Daughter	Father	6.9	8
Son	Father	1.7	2
Wife	Husband	6.0	7
Husband	Wife	6.0	7
Grand-daughter	Grandmother	0.9	1
Sister	Sister	1.7	2
Sister	Step-sister	0.9	1
Sister	Brother	0.9	1
Brother	Brother	0.9	1
Daughter-in-law	Mother-in-law	9.5	11
Daughter-in-law	Father-in-law	4.3	5
Son-in-law	Father-in-law	0.9	1
Niece	Aunt	2.6	3
Niece	Uncle	2.6	3
Niece-in-law	Uncle-in-law	4.3	5
Sister-in-law	Brother-in-law	1.7	2
Sister-in-law	Sister-in-law	1.7	2
First cousin	First cousin	0.9	1
Female neighbour	Old person	4.3	6
Male neighbour	Old person	2.6	3
Home help (female)	Old person	6.9	8

The two common stereotypes of unmarried daughter minding her ageing parents, or of ageing wife caring for her husband, are not borne out. The rate of spouses as

carers (12 per cent) seems low especially when compared with the figure of the Equal Opportunities Commission 1982 Study<sup>3</sup> which gave 27 per cent. I am not sure how one can account for this wide divergence. National samples might be a guide. Perhaps the high age structure of the cared-for in this sample causes the lower rate of spouses as carers. The rate of neighbours as carers was 6.9 per cent as opposed to 11 per cent in the English study. Then there were the Home Helps who were carers for 6.9 per cent. The Equal Opportunities Commission Study excluded Home Helps from interview. The reason for their inclusion in this study will be explained later.

It is worth examining the marital status of the daughters and sons who are the carers of their parents.

TABLE 5.6            CHILDREN CARING FOR PARENTS

	Daughters caring for Father or Mother	Sons caring for Mother *
Married	13.9 % (16)	0.0% (0)
Single	7.8 % (9)	6.9% (8)
Widowed	1.8% (2)	0.0% (0)
Separated	0.0% (0)	0.9% (1)

\* There were just two cases of sons caring for their fathers.

From the table it seems that single sons are as often carers as either single daughters or spouses.

The breakdown between blood and marriage relationship

was 48.8 per cent blood relationship, 34.4 per cent marriage relationship which includes 12 per cent of spouses and 13.9 per cent where there was neither blood or marriage relationship.

The carers of the handicapped were significantly more likely to be caring for other dependents than the carers of the elderly. 95.3 per cent of them look after others in the home as against 65.5 per cent of the carers of the elderly. In both cases approximately 50 per cent of the other dependents are under 15 years of age.

The majority of the carers of the handicapped live in the same house as the cared-for person (74.7 per cent). The remaining 25.3 per cent of the cared-for are in the residential school at St. Mary of the Angels, Beaufort, for five days of the week and return for weekends, mid-term breaks and school holidays. Among the carers of the elderly, 67.6 per cent live in the same house as the cared-for person, 26.1 per cent live in different houses from the cared-for person, 3.6 per cent are together during the day, and finally, 0.9 per cent live together at the weekends.

Most of the carers and the cared-for had a number of relatives living in the neighbourhood with other relations further afield in Ireland and abroad, illustrating the migration and emigration which are common here. Table 5.7 summarises.

TABLE 5.7. RELATIONS OF CARERS

Miles away:	Less than 2	2-3	4-5	6-10	11-70	Siblings in Ireland	Siblings Abroad
% Carers of Elderly	49.4	10.3	11.5	17.2	11.5	82.4	75.7
% Carers of Handicapped	38.2	14.7	17.6	10.3	19.1	80.2	70.9

Not quite half of the carers felt that they had a friend or helper who might be regarded as of special support. 42.1 per cent of carers of elderly and 40 per cent of carers of the handicapped said they had such a friend. These friends lived within two miles in 85 per cent of cases.

#### HISTORY OF CARING

The "life history" section came early in the interview when carers were asked to recall how they first came to assume the task of caring. After the 20-30 minutes spent on this "story", four or five specific questions were put if certain issues had not been mentioned already. From the accounts given by the carers of the elderly, 45 per cent of them always lived with the elderly person and it was "natural" that when he/she became feeble the carer assumed the role. For 35 per cent a crisis in the life of the old person, usually sickness, an accident or bereavement, caused the old person to come to live with the carer or occasionally the other way round. 7 per cent of carers returned from abroad to assume the caring role and 6 per cent

gave up a permanent job to do so.

With the carers of the handicapped, caring usually began with the birth of the child and a number of the mothers found the discovery of the handicap most traumatic.

The caring began in very trying circumstances in some instances and even years later the carers spoke with deep emotion about their early experiences.

When asked if there were others who might have taken on the caring task at the time, only small numbers felt there was: 14.5 per cent in the case of the carers of the elderly and 4.9 per cent in the case of the handicapped. Among the carers of the elderly who felt this way, 50 per cent pointed to a sister while one or two mentioned a son, a daughter-in-law, a niece and a neighbour. But the majority felt that the task fell naturally to them, that there was nobody else who could have or ought to have assumed it.

When queried as to how it was to them rather than to someone else the caring was entrusted their answers, outlined in Table 5.8 below, reflected a sense of family obligations while other motives began to come through also. The most common reasons given by the carers of the handicapped were expressed as follows:

*"I was his mother", "I was her mother and there was nobody else to take on the job", "Who else would do it, I being her mother?", "I was not prepared to put her into a residential school", "He was mine", "Since*

*I was his mother the task naturally fell to me", "She was one of the family and I was her mother, she was my child, she was my baby and my responsibility", "I brought her into the world", "I was there"*

With carers of the elderly similiar reasons were noted:

*"She is my mother", "He is my father", "I was the only daughter and I lived with my parents so naturally I looked after them when they grew feeble", "I had lived in the house with my parents-in-law since I married Sean", "Dan is my husband so isn't it only natural that when he got old I should look after him", "Because I was the last of the family at home, all the others had gone away", "Jim worked for the family and always lived in the house, he helped in the farm and it was natural that he should stay on when he grew feeble", "We are her daughters and she looked after us when we were young so we accept that we should help now when she needs care", "Pat my uncle reared me. I was always in the house", "I was single with no one to think of only myself", "I was the one at home and my sister came back here when her health broke down in England", "I was his wife and I still loved him and nobody else could humour him only myself", "Wasn't I her husband?", "Why should I throw him in some home when I'm able to do it?"*

Neighbours said things like:

*I'm her nearest neighbour", "Sure I know him most of my life and I was his neighbour".*

A home help who was the carer said, *"I lived close to him always and as a home help I know his needs as I always called there".* Another home help, *"I answered an ad. in the newspaper. She had become a live-in home help to an elderly couple whose daughter taught in a Dublin school.*

TABLE 5.8. HOW CARER WAS THE ONE TO WHOM THE  
TASK OF CARING WAS ENTRUSTED

(a) CARERS OF HANDICAPPED ( n = 86 )

<u>Reason Given</u>	<u>Number of Times Mentioned</u>
Carer was child's mother	63
Carer was child's father	3
There was nobody else to look after child	6
Carer did not want anyone else to take her place	6
Carer was child's sister	2
Carer saw it as a duty	2
Other	4

(b) CARERS OF ELDERLY ( n = 100 )

Close blood relationship mentioned (mother, father, sister, brother)	18
Carer was last member of family left at home; was youngest at home	18
Cared-for person had always been in house	13
Carer was only child/only daughter	5
Carer was single and at home	3
Carer was nearest neighbour	6
Carer was closest relative alive	4
Carer mentioned the personal qualities of the cared-for person which won them over	2
There was nobody else to take on task	7
Carer took on task as home help	7
Carer was appointed by member of family to take on task	2
Carer answered advertisement in the press	1
Other	11

These reasons for caring spring mainly from a sense of family loyalty and the duties of its members to each other. One of the factors often mentioned to account for help from outside the family seems to apply within the family also. Reciprocity which was noted by P. Abrams<sup>4</sup>, reciprocity between the generations, was an important factor here also. With most of them, caring seems to be seen as their natural role, part of family expectations. The word "naturally" cropped up frequently in their responses. The carers are reflecting a set of family and community expectations which they for the most part accept as valid and reasonable.

For some of them the caring has been going on for twenty years or more as Table 5.9 illustrates.

TABLE 5.9.            LENGTH OF TIME THE CARER HAS BEEN PERFORMING CARING ROLE

%	0-5 years	6-10	11-15	16-20	21-30	30+
Carers of elderly	37.1	14.7	12.1	6.5	3.8	0.9
Carers of handicapped	15.6	30.0	26.4	14.4	10.8	2.4

There were crisis points for some when a decision had to be made about placing the cared-for person in a residential setting or keeping him/her at home. This was a more frequent occurrence for the carers of the handicapped and it could happen very soon after the birth of the child or at school-going age when pressure could be brought to bear by husband, doctors, other members of the family and

and teachers or priests occasionally. The opening of day schools and the provision of transport in the past twelve years has lessened this pressure. 46.6 per cent of the carers of the handicapped reported such a crisis. Only 13.5 per cent of the carers of the elderly reported a similiar experience and it was due to illness on the part of the cared-for person or the carer in a few instances. In such cases doctors sometimes advised residential care. Carers could sometimes be stubborn. At other times they took the advice as being in the cared-for person's best interests. Some examples will illustrate the conflicts which faced the carers at these times. First the carers of the handicapped:

*"Some people said we should put our child away but we could never part with him"*

*"The doctor suggested a home but my husband and I decided to look after her ourselves"*

*"We felt at first that we would never put her away but when she was about four years old we found it impossible to cope with her"*

*"I thought about a home. When she was three our doctor told us she shouldn't start any school until she is seven at least so she is still at home"*

*"Being worried about his future and not wanting to burden his sister with the responsibility I searched around and found a place in a home for him"*

*"My husband thought it would be better to put him in a home"*

"Last November she was not well and was very depressed and I was not feeling well myself either. I found it hard to cope day and night"

"We didn't want to keep John at home, we wanted to give him every chance in life so we sent him to a home and school"

Short term care might well solve some of the difficulties mentioned.

With the carers of the elderly the feelings of the cared-for person seemed to come into play more:

"On a temporary basis we sent her into the District Hospital which is a long stay hospital but she wasn't happy there so my husband and myself decided to bring her out again and she remains with us"

"A nun wanted her to go into a home but we would not agree"

"About seven years ago she got old and became more feeble. My husband and I had to balance out responsibility between looking after her and our children. We decided however that she would stay at home despite the arguments for placing her in a residential home"

"When Kathy was in hospital she was extremely unhappy there. Her daughter had a full-time job so she decided that the best thing to do was get somebody to take care of her at home so I came to live with Kathy as a home help"

*"When my father-in-law got violent and threatened visitors we decided that he had to be placed in a psychiatric hospital for a time"*

I examined these difficult decisions and found that in the case of the elderly in 30.8 per cent of cases it was the carer alone who made the decision, in 23.1 per cent it was the cared-for person who decided while in 42.6 per cent the decision involved other family members and occasionally doctors. With the carers of the handicapped it was much more likely that husbands shared in the decision making in the majority of cases. Only 12.5 per cent of carers said they had acted alone in the decision. As a group, the carers of the handicapped were more likely to be married as we saw earlier thus enjoying more support in arriving at difficult decisions regarding the cared-for person.

I was interested in finding out if caring was a tradition within the carer's family so I asked if the carer's parents had looked after a grandparent, a handicapped child or a handicapped adult. The responses were as follows in Table 5.10

TABLE 5.10.      WHETHER CARERS' PARENTS HAD  
LOOKED AFTER OTHERS

( n = 199 )		Grandparent	Handicapped	Handicapped
%			Child	Adult
Carers of Elderly	YES	51.3	0.0	0.0
	NO	48.7	100.0	100.0
Carers of Handicapped	YES	29.1	3.7	2.4
	NO	70.9	96.3	97.6

( s = .002 )

There was extremely little previous experience of caring for handicapped but from the figure of more than 50 per cent of carers of the elderly whose parents before then had been carers, as opposed to 29 per cent of carers of the handicapped, leads one to suspect that example and tradition are being handed down in the case of the carers of the elderly.

In summary then the carers of the handicapped were almost all mothers while more than one quarter of the carers of the elderly were men. There was no significant difference in the age of the two groups. The carers of the elderly were a much more diverse group in their relationship with the cared-for person. When one excludes the men, the carers were almost all full-time housewives with only one in ten working outside the home even part-time. Very few of the carers felt that they had been unfairly cast in the role of carer. On the contrary, most seem to feel that they fell naturally into the part.

For a minority of the carers of the handicapped, the mothers, their initiation was traumatic. In a small proportion of the carers of the elderly their caring was the result of a crisis such as illness on the part of the cared-for person. Even as they described their initial involvement motives for caring began to surface. These seemed to be very much family based with good neighbourliness added in a minority of cases.

I now include four "life histories" or "caring biographies", the more correct description of Lewis and Meredith.<sup>5</sup> These illustrate the carer's personal experience of the costs and rewards of caring as well as giving their underlying motivation.

#### CASE A

Jeremiah O'Connor is 66 years of age and looks after his wife who is 68. His son and a brother-in-law live in the house with them.

*"Over the past ten years my wife Mary's health began to deteriorate. She got Diabetes and had to go to hospital in Killarney. She neglected it. She didn't take the Insulin every day as she was ordered. When one has Diabetes there is little healing when one gets another ailment. Mary's leg was burned with boiling water. Her leg got worse and there was little or no healing. Eventually the limb got so bad that it had to be amputated.*

*I did not feel good about the situation at that stage. It was a great shock to me to learn that my wife's leg had been removed. I was hopeful, however, when I learned that she would get an artificial leg. This hope did not last long. Mary's sight began to fail. One eye gave trouble and in the end, the sight went. I felt very distressed at that time. It was nothing compared to the distress I felt when she lost all her sight. She was now totally blind. It was then she became*

*totally dependent on me.*

*I felt that all this would be too much for me. I thought I could never cope. This all happened four years ago now. I never realised how much I was able to do. I began to wash her. Getting her up out of bed and putting her to bed was difficult at first, but soon it came naturally to me.*

*As time passed, I became more familiar with the situation. I was able to cope. It brought Mary and myself closer together. Our five children rallied round as well. There was a great sense of unity. Maurice, our son at home, is exceptionally good. I thank God for giving me the strength to do what I have to do."*

CASE B:

Mrs. Maureen O'Neill is 52. Her husband and her last child of three live at home, the other two boys are away at College. Maureen looks after her mother, Mrs. Molly O'Leary, who is 91 and lives with them in their house now.

*"About two years ago, my mother got a mild stroke and then, about a year ago, she got another very severe stroke. Because of this, she lost the use of her limbs and also became incontinent and soils. She lived with my brother in Castlegregory until about eight months ago. He retired here early thinking that, perhaps, he could look after her. I used to hate to go home to see her. She used to be so dirty and huddled over the fire. I hated to see her dirty. Then about eight months ago, she had to go into Dingle hospital. She was miserable there and cried all the time. I think she was disappointed that she should be thrown there and that none of her own would keep her. She has another sister in that hospital and has two other sisters and a brother in Castlegregory. They all advised me that I couldn't manage her at all. They said I was mad. My husband and myself discussed it and we felt that we couldn't leave her there. My brother couldn't manage her any more and my other sister lives in a pub and has a large family. My mother was always very anti-drink and there was no way she'd go there. Mind you, we were never too close. She was in fact much closer to my other sister in the*

pub, though anytime she had ever been sick it was to me she always turned. In the beginning she broke our hearts. She didn't want to be here but at home in Camp. Visitors always came to see her, too many at times. Indeed I find it very hard on Sunday sometimes, when all the visitors turn up together. But the visitors used to be uncomfortable in the beginning because she used to want to go home with them. It frustrated me too, because I knew that no matter how much I did for her, changing her, cleaning her, she wasn't satisfied and would prefer to be thrown in a dirty heap at home in Camp. A few months ago then, I had to have a break so she spent ten days in the District Hospital. I needed the time to myself and my husband and myself planned to go away for a few days. As it happened we didn't go because I was in and out to see her every day. She was happy enough for the first couple of days but then the tears all started again. She was delighted to be out and to be leaving the hospital but she thought she was going home to Camp and she was very disappointed to find herself, in her own words, "landed here again". I feel guilty about her as I feel she deteriorated very much while she was there. She was put into a ward with very old people who couldn't talk to her. The Staff didn't have time to get around to her and she lost her footing and it was gone altogether as a result. I think she's getting much weaker now. She used to be great company telling stories about the old days and so on. Now she's beginning to wander a bit and her voice is weakening. She used to come out here to the living-room and sit by the fire but not anymore. Then for a while, she'd get out on the chair for part of the day, but now five minutes is about enough for her. Though the children were deprived of their study room and many of the family outings which we used to have, they are very fond of her and love to bring in their friends to see her."

#### CASE C

Nora Herman is 41. She is married to a factory worker and she has five children, the eldest aged 21 and the second youngest 15, and then Brian, her youngest son, who is 3½.

"I was 37 when I became pregnant with Brian. It was a great surprise as the youngest was twelve. But we were delighted and the children were delighted and they told all their friends they were getting a new baby. When he was born I thought his head looked large and I said this

to the nurse. The doctor told my husband and then he told me. I cried for two whole days. I cried for the disappointment of my other children and out of fear. After all, we were not getting any younger. Then we brought him home and my mother died and my husband came down with a suspected tumour in the lung. We thought he had cancer. This was the worst time in my life. The neighbours came in and told me I would be better off without this child and I had to ask one neighbour to please leave my home. One neighbour said, "he looks like a little old Chinaman". Miraculously my husband got better. The tumour disappeared. He got a clean bill of health.

More and more, Brian began to change our lives. He was very sickly, you know, and he had a very large tongue which used to choke him. When Brian was two we became members of the Down's Syndrome Association which issues a Newsletter now and again. There was an article in one of the Newsletters by Professor Browne who said that all Down's Syndrome sufferers who had long tongues should have an operation to shorten them, thereby allowing them to swallow more easily. Brian had this operation August last. We think he is the first one in Ireland and certainly he is the first one in Kerry to have this operation and he is now eating solid food. The children adore him and we are all so proud of him. We know he is an intelligent child. You can't imagine how affectionate he is and all we want now for him is that he will be able to reach his full potential. He is included in all our activities and he knows he is the centre of attraction. We want the best for all our children and we hope to make Brian as independent as possible and we have great hope for the future as we know that new discoveries are being made all the time in this area."

#### CASE D

Maura Murphy is 49. She is a Primary School Teacher and has five children. Her husband is a butcher. Her daughter, Orla, is 10 and she is the cared-for person here.

"I never got over the shock of having a mentally retarded child. Looking back now I can honestly say it wasn't so much the shock of having her. It was more the way I was told. The Paediatrician threw it at me. That is how I can only describe

it. He said, "your child is a mongol and what can you expect at your age". I think I fainted at that stage. However there was a Nun there who was very kind to me and I regretted that she didn't get a chance of breaking the news to me. I was 39 when she was born. Most mothers have a fear of having a handicapped child, but I must confess that the thought never entered my head. I already had four daughters and I had given birth to each of them without any trouble. So I had no reason to believe that this would be any different. Before she was born I used to play a lot of Bridge and I was anxious to have the baby so that I could get back to Bridge and to my friends again. That was ten years ago and I haven't been able to play Bridge since. I was left out of hospital after three days and they kept the baby two weeks for me. I told them I didn't want to bring her home, that they could do what they liked with her. At that stage if a tinker going the road wanted her, I'd have given her away. The Nun at the hospital told me not to leave her at the hospital too long because it was vital to form a bond quickly. I brought her home after two weeks, and for twelve months I didn't have any feeling for her at all. When she was around a year old, I was going to Cork one morning and Orla was sick. I phoned the doctor and left the housekeeper in charge and went off. I would never have done that with one of the others. When I came home, she was in hospital and was critical with pneumonia. The doctor was very annoyed at the fact that I had gone off to Cork without a second thought. I spent the night with her in hospital and prayed that night that if she got well, I would make the best of things and would be a better mother to her. I haven't looked back since that night. Believe it or not, I am a better person because of Orla, less interested in material things and Orla has turned out to be the most loveable and kind of all my children."

NOTES

1. This study entitled, *"Carers and Service: A Comparison of men and women caring for dependent elderly"*, Charlesworth, A., Wilkin, D., and Dune, A., Equal Opportunities Commission 1982, provides some interesting comparisons. The study involved 157 cases.
  
2.  $s = 0000$  on Chi Square Test. To simplify from here on, unless otherwise stated "significant" difference will be taken to be  $s = 0000$  on this test.
  
3. Charlesworth, A., et al., 1982, op.cit.
  
4. Abrams, P., Abrams, S., Humphrey, R., and Snaith, R., 1981, *"Action for Care: a review of Good Neighbour schemes in England"*, Berkhamsted, Herts., The Volunteer Centre,  

In his first study of a Good Neighbour Scheme, Abrams emphasised the centrality of reciprocity. "The notion of 'ordinary people wanting to help each other' rests on a simple expectation of reciprocity. Whether the return is made now or in the future, there seems to be a fundamental belief that help can earn help. The negative aspect of this, of course, is a rather overt belief that help should earn help, that payment is due."
  
5. Lewis, J., and Meredith, B., 1988, *"Daughters who Care"*, Routledge, London, p.14

CHAPTER 6

THE CARED-FOR PERSONS : BASIC DATA

Of the 113 cared-for elderly, just slightly more than two thirds were women (68 per cent). The handicapped cared-for persons, on the other hand, were 54 per cent male and 46 per cent female. This bears out the greater rate of women in the older age groups in all Western societies. And within this elderly sample the higher age group predominated.

Their age is, in itself, an indication of their need for care and support from family and community. It is generally agreed in the literature that the over 75s or, more recently, the over 80s<sup>1</sup>, will be extremely unlikely to be able to cope without some help at least. Tables 6.1 and 6.2 show the elderly in this sample to be more likely to be over 80 than under it. The national figure for the over 75s was 36 per cent of all elderly in 1981, for over 80s it was 17 per cent.<sup>2</sup>

TABLE 6.1 : AGE OF ELDERLY CARED-FOR PERSONS

<u>YEARS</u>	<u>NUMBER</u>	<u>%</u>	<u>CUMULATIVE %</u>
58	1	0.9	
63 - 64	2	1.8	2.7
65 - 69	9	7.7	10.4
70 - 74	16	13.8	24.2
75 - 79	20	17.2	41.4
80 - 84	29	25.0	66.4
85 - 89	26	22.4	88.8
90 - 94	11	9.5	98.3
95 - 97	2	1.7	100.0

( n = 113 )

TABLE 6.2 : THE OLD ELDERLY \*

% of Cared-for Elderly  
persons aged:

90+	11.2 %
85+	33.6%
80+	58.6%
75+	75.8%

\* 1981 Census      36% of elderly were 75+  
                         17% of elderly were 80+

The 86 cared-for persons among the handicapped go from 2½ to 44 years of age but the majority are under 14 (55.7 per cent) with the very great majority of the remainder under 30. A comparison between the cared-for persons ages and those of their carers is shown in Table 6.4. While there is no significant difference between the ages of the carers, the two sets of cared-for persons are at the opposite ends of the scale. Table 6.3. shows the ages of the handicapped cared-for persons.

TABLE 6.3: AGES OF HANDICAPPED CARED-FOR PERSONS

<u>YEARS</u>	<u>NUMBER</u>	<u>%</u>	<u>CUMULATIVE %</u>
2½ - 7	14	16.2	16.2
7 - 14	34	39.5	55.7
14 - 18	16	18.6	74.3
18+	22	25.6	100.0

( n = 86 )

TABLE 6.4: AGES OF CARERS AND CARED-FOR PERSONS : COMPARISONS

<u>YEARS</u>	<u>CARERS</u>		<u>CARED-FOR PERSONS</u>	
	% <u>Elderly</u>	<u>Handicapped</u>	% <u>Elderly</u>	<u>Handicapped</u>
1 - 19	0.9	0.0	0.0	76.7
20 - 44	36.9	44.4	0.0	23.3
45 - 64	40.5	54.0	2.7	0.0
65 - 74	18.0	3.6	21.2	0.0
75+	5.4	1.2	76.1	0.0
n =	113	86	113	86
%	56.8	43.2	56.8	43.2
	s = 0.3811		s = 0.0000	

The marital status of both groups is given in Table 6.5

TABLE 6.5 : MARITAL STATUS OF CARED-FOR PERSONS

%	Elderly	Male	Female	Handicapped
Married	26.8	30.0	25.6	0.0
Widowed	45.5	30.0	51.2	0.0
Single	27.7	40.0	23.2	100.0

( n = 199 )

These figures come very close to the national figures for the over 75s which are: married, 28 per cent, widowed, 42 per cent and single, 25 per cent.<sup>3</sup>

As with the carers, the majority of the cared-for persons had been housewives while the men had been farmers or unskilled manual workers for the most part.

The relationship of the carers to the cared-for person

has been described in the previous chapter. It is worth while, I think, to present the relationship from the other side here. Table 6.6 gives this picture from the cared-for person's perspective in this case.

TABLE 6.6 : RELATIONSHIP OF CARED-FOR PERSON TO CARER

	%
Cared-for Person is Mother of carer	24.1
" " " is spouse of carer	12.5
" " " is Father of carer	8.0
" " " is Sister of carer	8.9
" " " is Brother of carer	1.8
" " " is Aunt of carer	2.7
" " " is Uncle of carer	1.8
" " " is Mother-in-law of carer	9.8
" " " is Father-in-law of carer	5.4
" " " is Grandmother of carer	0.9
" " " is Sister-in-law of carer	1.8
" " " is Brother-in-law of carer	0.9
" " " is Neighbour/friend of carer	6.1
" " " is Other relative of carer	6.3
" " " is recipient of Home Help	7.1

The majority of the cared-for persons lived with their carers with the exception of those handicapped (25 per cent) who spent the five day school week in the residential centre and 19.8 per cent of the elderly who lived alone. This seems to be a high figure in the case of the latter since the national figure is only 18.4<sup>4</sup> but in my previous study of 1977 in this area 25 per cent of the over 65s lived alone. Both Wenger and Hunt had a higher figure for their English and Welsh populations.<sup>5</sup> Nevertheless the high

age of this sample would, one should have thought, make living alone extremely difficult. Even more surprising is the fact that the majority of these elderly who live alone are in their eighties. Table 6.7 breaks down the twenty two cases. Almost 60 per cent were over 80.

TABLE 6.7 : AGE OF ELDERLY LIVING ALONE

AGE	58 - 75	75 - 85	85 - 90	90+
	22.7%	45.4%	27.2%	4.5%
n= 22	(5)	(10)	(6)	(1)

The handicapped lived in significantly larger households than the elderly as can be seen from Table 6.8.

TABLE 6.8. : NUMBER OF PEOPLE IN HOUSE WITH CARED-FOR PERSON

Household size	Elderly %	Handicapped %
1	19.8	0.0
2	27.9	1.2
3	18.9	13.6
4	10.8	14.8
5	9.0	11.1
6	1.8	14.8
7	7.2	17.3
8	3.6	7.4
9	0.0	7.4
10	0.0	3.7
11	0.9	3.7
12	0.0	3.7
13	0.0	1.2

RELATIVES

Approximately half of the cared-for persons have a relative living within one mile of their home. In the case of the

elderly this included a son for 20 per cent, a daughter for 12 per cent, a brother for 12 per cent, a nephew for 17 per cent and a first cousin for 16 per cent. Table 6.9 fills out the picture to include the relatives of the two groups of cared-for including siblings at home and abroad.

TABLE 6.9 : RELATIVES OF CARED-FOR PERSONS

Miles	Less than					Siblings	
	2	2-3	4-5	6-10	11-70	in Ireland	Siblings Abroad
%Elderly	54.2	6.0	15.7	12.0	12.0	46.4	60.4
%Handicapped	35.8	14.9	20.9	10.4	17.9	36.0	23.5

The carers also identified a friend of the cared-for person who was of special support in 44 per cent of elderly and 24.7 per cent of the handicapped. In this the two groups differed significantly but as seen in the last chapter, the carers had much the same proportion of such friends, approximately 40 per cent in each category. It would seem that the carers of the handicapped do not think their cared-for persons have many real friends in the community.

The next question is to get a general picture of the degree of incapacity of the cared-for persons. This was done by means of questions on a list of activities believed to constitute normal living for a healthy active old person or growing child or young person in the case of the handicapped. The carer was asked to say whether the cared-for person could perform these activities alone or whether

supervision or actual help had to be given in their performance. It can be assumed that there is nobody who knows the cared-for person's "form" better than the carers. The carer is "on the spot" day in day out. She will know the doctor's and the public health nurse's opinion of their state of health and will probably have hourly bulletins from the cared-for person on how he/she is feeling. The carer speaks, as I said already, with "the authority of relevance". She may of course be biased about the dependence of the cared-for person in certain cases. Table 6.10 gives the various personal and household tasks and the degree of independence or dependence of the cared-for elderly persons.

TABLE 6.10 : PERSONAL AND HOUSEHOLD TASKS  
ELDERLY CARED-FOR PERSONS

<u>%</u>	<u>Can do on own</u>	<u>Under</u>	<u>Only</u>
<u>Does cared-for person have</u> <u>difficulty in:</u>	<u>No difficulty</u>	<u>Supervision</u>	<u>with</u> <u>help</u>
Having all-over wash/bath	51.3	4.4	36.3
Washing hands/face	78.8	4.4	16.8
Putting on shoes/stockings	75.0	4.5	20.5
Doing up zips, buttons	70.5	8.9	20.5
Dressing other than above	71.4	9.8	18.8
Getting to and using W.C.	82.1	3.6	14.3
Getting in and out of bed	83.9	4.5	11.6
Feeding self	89.3	6.3	4.5
Shaving (men)			
Combing hair (women)	76.4	6.5	18.2
Cutting toenails	34.2	5.4	59.5
Negotiating steps/stairs	59.6	11.7	28.7
Getting around the house	80.6	5.6	13.9
Getting out of doors on own	51.5	14.1	34.3
The taking of prescribed medicine	40.5	22.6	36.9

The degree of dependence can be measured against Wenger's

sample<sup>6</sup> where 7 per cent need help taking a bath or an over-all wash, 7 per cent need help getting out of doors on own, 5 per cent need help negotiating steps while only 3 per cent or less have to be helped with washing hands and face, putting on shoes and stockings, doing up buttons and zips, dressing, going to and using the W.C., getting in and out of bed, eating, brushing hair or shaving, getting around the house. Cutting toenails seems to present one of the most difficult problems for elderly people and in Wenger's<sup>7</sup> sample, 17 per cent had to be helped. In Hunt's study<sup>8</sup> it was 27 per cent. It seems clear from the comparison between these two samples that the cared-for persons in this study are reported to display a much greater degree of dependence than a "normal" population of over 65s. Of course the accounts in one came from the elderly themselves who are thought to understate their disabilities and overstate their health as Anderson et al.<sup>9</sup> found with rural people. Tinker<sup>10</sup> puts forward the theory that since ill-health is associated with the negative stereotype of old age, elderly people refuse, as long as possible, to accept this label and continue to profess that they are well. Are the elderly more truthful to their carers than to doctors or social science interviewers? Are carers apt to exaggerate the degree of disability in order to show how much they are doing or even to feel that they are greatly needed? Or do carers sometimes produce dependence by doing too many things? These are interesting questions some of which

will be teased out later.

When asked to rate the health of the cared-for persons, the carers described it as "Generally good", 41.6 per cent, "Fair only", 27.4 per cent, "Varies a lot", 15.9 per cent, "Poor", 10.6 per cent, "Very poor", 5.3 per cent.

Among the elderly in Wenger's<sup>11</sup> and Hunt's<sup>12</sup> studies less than 3 per cent are bedfast. In this study 7 per cent are bedfast. This was slightly less than the rate in the main residential home for Co. Kerry, St. Columbanus' Home, Killarney, former County Home and Workhouse originally. It has been modernised and new buildings have been added in the past twenty years. The comparative figures between the elderly in the community and those in this residential home are given in Table 6.11.

TABLE 6.11 : BEDFAST AND HOUSEBOUND ELDERLY

	Present Study	St. Columbanus' Home Killarney
Cared-for person is:	n = 113	n = 239
	%	%
Bedfast	7.1	9.4
Bed/Chair bound	17.5	20.0
Permanently housebound	38.4	91.5
Able to get up for up to two hours each day	6.7	10.6
Able to get up for six hours	16.2	16.6
Able to get up for normal day	77.1	54.7
Never able to go for short walk	29.4	91.5
Very rarely goes for short walk	28.4	91.5
Goes for a short walk once a week	5.5	8.5
Goes for a short walk most days	36.7	8.5
Not capable of being alone even for short periods	29.2	-

The comparison shows the elderly in the community to be more mobile generally than those in the residential home. The regime in St. Columbanus' Home is quite liberal and the residents can walk into town and do shopping or enjoy a drink. If the elderly in the study were forced to go into residential care it is to St. Columbanus' Home many of them would go. A certain lingering stigma of the County Home and Workhouse remains among the elderly in Kerry in relation to this institution.

To return to Table 6.11, the 7 per cent who are bedridden plus the further 10 per cent who are chairbound and those

who can only get up for two hours each day ( 6.7 per cent ) constitute more than one quarter who must need a very high level of care. Considering that 29.2 per cent are not capable of being on their own even for short periods, full-time care is required in the case of at least a third of the elderly cared-for persons.

The problem of incontinence will probably be thought to have been introduced in far too "genteel" a manner - the carers were asked "if there were problems of incontinence". 17.9 per cent said there were. The subject came up a number of times in the life histories where carers found this particularly trying. I felt that this area was a little bit too delicate, or should I say indelicate, for cross-examination and the interview might be regarded as too inquisitive. This could damage rapport in some cases. So I decided to tread gently.

When asked if the cared-for persons suffered from any specific disease 61.7 per cent of the carers said they did and mentioned at least one and sometimes combinations of different diseases. Arthritis was mentioned by 16 carers, diabetes 5 times; heart conditions, the after-effects of stroke, high blood pressure, hypertension, hardening of the arteries were each mentioned three or four times. There was one case of asthma, one case of Parkinson's disease, four were totally blind while a further six had only partial sight. Two suffered

from severe deafness. Depression and nervous disorders were mentioned five times. "Senility" was mentioned in relation to two of the cared-for persons.

The elderly in this study are as we saw in the higher age brackets ( 80+ ) for the most part. Despite this fact many of them still retain a good degree of independence and are able to do many things for themselves and so many may not need a great deal of care and supervision. But there is a section, numbering about one third, who are in need of full-time care and attention. Without carers in the family or in the community it seems fair to say that they would be candidates for residential care.

#### THE MENTALLY HANDICAPPED CARED-FOR PERSONS

As mentioned earlier the 86 mentally handicapped were chosen at random from a list of all the known moderately and severely handicapped in County Kerry in 1985. The carers were asked a set of questions about their abilities and disabilities and their need for help with various aspects of daily living.

Bayley<sup>13</sup> found that there were two factors which proved crucial to decisions parents made to seek residential care for their handicapped child. The most important was behaviour problems. Bayley<sup>14</sup> states, "The behaviour

of the subnormal was the most important single factor leading to hospital admission, dwarfing all others ..... in every group there were well over twice as many with a serious behaviour problem who were in hospital as there were at home." Behaviour problems included aggression, antisocial sexual behaviour, crime, behaviour problems with younger siblings. The other factors which predisposed parents or other carers to place their child in a hospital for the handicapped were the death or illness of a parent. Social reasons which include unsatisfactory home conditions, inadequate parental control and nursing problems came third among predisposing factors.

The responses of the carers to a number of questions relating to the cared-for person's abilities to perform different tasks are given in Tables 6.12 to 6.15.

TABLE 6.12 : CONTINENCE

(n = 86) %	Frequently	Occasionally	Never
Wets at night	10.6	16.5	72.9
Wets during day	8.3	10.7	81.0
Soils at night	4.8	8.3	86.9
Soils during day	6.0	13.1	81.0

TABLE 6.13 : MOBILITY

(n = 86) %	Not at all	Not upstairs	Upstairs and Elsewhere
Walk with help	8.6	0.0	91.4
Walk by self	4.8	2.4	92.8

TABLE 6.14 : SELF CARE

<u>%</u> (n = 86)	Not at all	With help	Without help
Feed self	2.4	8.2	89.4
Wash self	4.7	40.0	55.3
Dress self	3.5	36.5	60.0

TABLE 6.15 : PERSONAL AND HOUSEHOLD TASKS

<u>%</u>	Can do on own No difficulty	Under Supervision	Only with help
Does cared-for person have difficulty in:			
Having all-over wash/bath	29.8	33.3	36.9
Washing hands/face	65.3	24.7	20.0
Putting on shoes/stockings	56.5	10.6	32.9
Doing up zips, buttons	48.2	11.8	40.0
Dressing other than above	54.8	21.4	23.8
Getting to and using W.C.	69.4	21.2	9.4
Getting in and out of bed	90.6	4.7	4.7
Feeding self	90.6	5.9	3.5
Shaving (men); Combing hair (women)	61.0	15.3	23.7
Cutting toenails	15.7	7.2	77.1
Negotiating steps/stairs	85.4	6.1	8.5
Getting around the house	96.4	0.0	3.6
Getting out of doors on own	79.3	14.6	6.1
Taking prescribed medicine	83.3	-	16.7

The cared-for person's vision was described as poor in 21.2 per cent of cases and normal in 78.8 per cent of cases. With regard to hearing, 2.4 per cent were reported to be deaf or almost deaf, 4.7 per cent were said to have poor hearing and 92.9 per cent to have normal hearing. Speech was the next faculty to be examined. 9.5 per cent "never said any word at all", 34.5 per cent had odd words only ( occasionally, these were choice words

as it happens ! ) and 54.8 per cent spoke normally in sentences. 1.2 per cent could talk but didn't.

Coming to reading ability, 51.8 per cent could not read at all, 38.8 per cent could read a little and 9.4 per cent could read the newspapers. 47.1 per cent could not write, 45.9 per cent could write a little, 7.1 per cent could do their own correspondence. 38.1 per cent were unable to count, 51.8 per cent could count a little and 16.5 per cent understood money values.

Clarity of speech came next and 7.5 per cent of cared-for persons were said to be difficult to understand even by close acquaintances and impossible for strangers; 41.5 per cent were said to be easily understood by close acquaintances but difficult for strangers to understand and 50.9 per cent were said to be clear enough to be understood by everybody.

When a comparison is made between this sample and Bayley's this group seems to have slightly less who are unable to walk at all (8.6 v 13.1). In regard to speech it is difficult to make a direct comparison with Bayley's handicapped. 25 per cent of his sample could not talk. In this study, 9.5 per cent could not say a word at all while 34.5 per cent could only say an occasional word. For one boy this word was "Capital" and it described all the things which pleased him. Another boy's only word was "Hot". The proportion of children suffering from

blindness and deafness were similiarly small in both studies.

Referring to incontinence Bayley<sup>15</sup> says, "Incontinence in children is more acceptable than in adults. Many of the children who were partly incontinent would be learning and becoming better controlled. In the adults, any incontinence probably meant incontinence for good, which is a daunting, expensive and exhausting proposal for the parents or others looking after the subnormal. It is easy to appreciate why a relative would be reluctant to take on a subnormal if he were incontinent." 19 per cent of Bayley's group were reported to be incontinent as against 28 per cent in this study on the general question mentioned earlier with regard to "problems with incontinence". From Table 6.12 it would seem, overall, this group has slightly more problems of incontinence than Bayley's.

The important subject of behaviour patterns must now be examined since it can be so decisive as to whether or not the mentally handicapped will remain in the community. The responses on behaviour are given in Table 6.16.

TABLE 6.16 : BEHAVIOUR DIFFICULTIES

	To a marked degree %	To a lesser degree %	No %
Hits out or attacks others	3.5	21.2	75.3
Tears up pages, magazines, clothing, damages furniture	9.4	18.8	78.1
Extremely overactive, paces up and down restlessly, does not sit down for a minute	10.7	17.9	71.4
Constantly seeking attention, will not leave adults	8.3	27.4	64.3
Continually injures self physically, e.g., head banging, picking at sores, beating eyes	4.7	3.7	91.8

It is difficult to estimate the extent and seriousness of these behaviour problems. Those who "misbehave" to a marked degree must surely be a handful for their carer and others. Those who do these things to a lesser degree are more manageable, one thinks, but it must be particularly difficult for carers in public with these cared-for persons. When asked what problems presented the greatest difficulties, carers put behaviour problems at the top of the list, speech difficulties next, then lack of mobility, and finally incontinence.

A point I thought worth investigating was whether the carers thought that the cared-for persons could do more for themselves than they actually do. I wondered if, perhaps, the carers might be making the cared-for more dependent than might otherwise be the case. As might be expected neither set of carers agreed. Only 16.7 per cent of the

carers of the handicapped and 3.7 per cent of the carers of the elderly felt that the cared-for could walk more or walk more often if they wanted to. What was very interesting was the different responses of the two groups to the question whether there were things which the cared-for persons did on their own, which while good for their independence, gave the carers more trouble than if they did them for their charges. Only 6.7 per cent of the carers of the elderly thought this to be the case but 44.2 per cent of the carers of the handicapped felt that this was the case. Perhaps these carers are at some pains to develop independence in a way which the other carers are not? It seems that the carers of the handicapped consciously promote greater independence whereas those of the elderly were not so motivated. Carers of the elderly probably cannot look forward to progress in independence or only to temporary independence at best. But carers of the handicapped do look forward to improved performance as parents do in the case of normal children, and so they would be more tolerant and patient about allowing their cared-for to do things for themselves as part of the education or training process.

The carer was asked to recall the moods and the behaviour of the cared-for person during the week previous to the interview. The responses are contained in Table 6.17

TABLE 6.17 : THE BEHAVIOUR AND GENERAL FORM OF THE  
CARED-FOR PERSON OVER THE PREVIOUS WEEK

%			
( n = 86 )	A lot	Sometimes	Hardly at all/never
Restless	4.7	25.9	69.4
Irritable	3.6	29.8	66.7
Aggressive	3.5	20.0	76.5
Obstinate	10.7	48.8	39.3
Affectionate	91.8	7.1	1.2
Appreciative	77.4	16.7	6.0
Forgetful	7.1	41.7	51.2
Impatient	16.5	44.7	38.8
Cheerful	88.2	9.4	2.4
Repeating requests over again and again	34.5	27.4	38.1
Carer lost temper with cared- for person during past week	2.4	22.6	75.0
Carer had to restrain cared- for person	4.8	25.0	20.2
Carer was frightened of cared-for person	1.2	1.2	97.6
Carer was embarrassed by cared- for person	1.2	9.5	89.3
Carer found it difficult to leave cared-for person	7.2	26.5	66.3

While these responses show that the cared-for persons can be annoying through "repeating things over again and again" and though a certain amount of impatience and obstinacy comes across, these are more than counter-balanced by the very positive things said about them by the carers. There seems to be a sense of loyalty at work here. One wonders if the parents of normal children would give as high a rating to them as these mothers of the handicapped did? The finding that a mere 2.4 per cent of the carers lost their tempers often and only 22.6 per cent occasionally

did so causes one to wonder how reliable this examination of conscience is ! However, we will see at a later stage that the carers regard their development of patience and understanding as one of the benefits which they have from caring.

A comparison between the 25 per cent who are in five day residential care and those at home full-time showed no significant difference in the measures on over-all health, physical disabilities or general behaviour. The significant differences were in relation to restlessness, irritability and impatience. Those in residential care were reported to have been significantly less restless, irritable and impatient than the others. And the carers had lost their tempers less with those in residential care than with the others. Since these interviews took place while the children were on their summer holidays in 1985, the differences may be due to less strained nerves on the part of the carers whose burden of caring may have been easier.

In summary, the elderly group are, by their age in the first place and by the carers' reports in the second, a dependent people or likely to become so with the advance of the years. About one third need full-time care. The other two thirds, while maintaining a fair degree of independence in daily activities, are dependent to some extent and this dependence must necessarily increase in the majority of cases because of their advanced age.

From comparative studies with samples of over 65s in England, Wales and Ireland, this group as a whole can be seen to be in need of some degree of care and support and a minority of about a third are in need of full-time care. Even without major crises the prognosis for the remainder must be increasing dependence.

The handicapped sample, not surprisingly, were a more active group physically than the elderly but here again there was a great deal of caring or "tending", as Parker<sup>16</sup> calls it, and supervision required from the carers. In so far as detailed comparisons can be made, the sample seemed to be generally in line with Bayley's British sample.

The study of carers which was conducted by the National Council for the Aged<sup>17</sup> in 1987 concluded that 17 per cent of the over 65s in the Republic of Ireland are dependent on their families for as they put it "a significant amount of care at home from a relation", as against 5 per cent who are in residential care. The remaining 78 per cent were leading independent lives. On the basis of 17 per cent of the total age group over 65 receiving care, the high average of my sample would suggest that if I have erred in regard to their need for care, I have done so on the conservative side. Lewis and Meredith<sup>18</sup> have identified three stages in the "caring sequence". Theirs is a useful contribution as it seeks to situate the carer in (i) semi-care (ii) part-time full care and (iii) full-

time care. Sometimes these stages follow gradually with increasing age, at others a further stage is "triggered" by crisis such as sudden illness, death of cared-for person's partner. I should have thought that something like one third of the elderly in this study are at stage (iii), while the great majority of the remainder would be at stage (ii).

NOTES

1. Wenger, G.C., 1984, *"The Supportive Network"*, George Allen and Unwin, London.  
"It seems apparent that the availability of supportive relatives is essential in keeping the majority of the over 80s in the community" (p.182)
2. Census of Population, 1981, Vol.2, Central Statistics Office, Dublin
3. Census of Population, 1981, op.cit.
4. Census of Population, 1981, op.cit.
5. Wenger, G.C., 1984, op.cit., p.8
6. Wenger, G.C., 1984, op.cit., p.29
7. Wenger, G.C., 1984, op.cit., p.30
8. Hunt, A., 1978, *"The elderly at home: a study of people aged sixty five and over living in the community in 1976"*, Social Survey Division, OPCS
9. Anderson, W., et al., 1974, *Geriatric Medicine*, Academic Press, London
10. Tinker, A., 1981, *"The Elderly in Modern Society"*, Longman, London
11. Wenger, G.C., 1984, op.cit., p.27
12. Hunt, A., 1978, op.cit., p.70
13. Bayley, M., 1973, *"Mental Handicap and Community Care"*, Routledge and Kegan Paul, London
14. Bayley, M., 1973, op.cit., p.123
15. Bayley, M., 1973, op.cit., p.120

16. Parker, A., 1981, "Tending and Social Policy", in Goldberg, E.M., and Hatch, S., *"A New Look at the Personal Social Services"*, Policy Studies Institute, London, pp. 26-30
17. National Council for the Aged, *"The Caring Process: A Study of Carers in the Home"*, (to be published)
18. Lewis, J., and Meredith, B., 1988, *"Daughters Who Care"*, Routledge, London, pp. 33, 180-182

CHAPTER 7HELP NEEDED AND HELP PROVIDED

The actual help needed by the cared-for persons and an attempt to assess the degree of help given by the carers, their spouse, other family members within and outside the household, the neighbours and the social services are set out in this chapter. I depend on the reliability of the carer's report in each case. The carer may on the one hand exaggerate her own role in the caring process in order to impress the interviewer. On the other hand the carer may exaggerate the contribution of spouse or family or others out of a sense of loyalty, of not wanting to let the others down to an outsider.

The picture of care is built up with reference to a list of personal and household tasks some of which the cared-for person can do independently but others where he/she needs supervision or actual help to perform. In each case, the helper is identified. Table 7.1 shows the pattern of caring in regard to personal tasks. The "others" who help are further identified in Table 7.2.

TABLE 7.1

Cared-for Persons and Difficulties with Personal Tasks

%	ELDERLY								MENTALLY HANDICAPPED							
	CAN PERFORM TASK			WHO HELPS?					CAN PERFORM TASK			WHO HELPS?				
	On Own	With Super-Vision	Only with help	Carer alone	Carer & Others	Others in House	Others outside House	On own	With Super-vision	Only with help	Carer alone	Carer & Others	C.F.P. & Others	Others in House	Others outside House	
Taking bath	59.3	4.4	36.3	34.8	8.7	7.2	13.0	29.8	33.3	36.9	42.4	4.5	34.8	4.5	0.0	
Washing hands/face	78.8	4.4	16.8	29.6	7.3	3.7	0.0	55.3	24.7	20.0	23.2	0.0	35.7	1.8	0.0	
Putting on shoes/stockings	75.0	4.5	20.5	34.5	6.8	5.3	0.0	56.5	10.6	32.9	13.0	0.0	46.3	1.9	0.0	
Buttong/zips	70.5	8.9	20.5	39.0	8.5	5.1	0.0	48.2	11.8	40.0	22.8	0.0	43.9	1.8	0.0	
Dressing other than above	71.4	9.8	18.8	36.1	8.2	4.9	0.0	54.8	21.4	23.8	18.5	0.0	44.4	0.0	0.0	
Getting to & using WC	82.1	3.6	14.3	22.2	7.4	3.9	1.9	69.4	21.2	9.4	19.6	0.0	27.5	0.0	0.0	
Getting in & out of bed	83.9	4.5	11.6	19.6	5.9	5.9	2.0	90.6	4.7	4.7	6.7	0.0	11.1	0.0	0.0	
Feeding self	89.3	6.3	4.5	14.9	10.6	0.0	0.0	90.6	5.9	3.5	2.4	0.0	17.1	0.0	0.0	
Shaving/Combing hair	76.4	5.5	18.2	19.3	8.8	8.8	5.3	61.0	15.3	23.7	15.0	2.5	32.5	5.0	0.0	
Cutting toenails	34.2	5.4	59.5	49.5	7.7	11.5	15.4	15.7	7.2	77.1	51.4	4.3	31.4	5.7	0.0	
Up & down steps	59.6	11.7	28.7	34.0	17.0	11.3	1.9	85.4	6.1	8.5	9.1	0.0	18.2	0.0	0.0	
Getting around house	80.6	5.6	13.9	23.3	9.3	4.7	2.3	96.4	0.0	3.6	2.7	0.0	5.4	0.0	0.0	
Getting out of doors	51.5	14.1	34.3	45.0	13.3	6.7	6.7	79.3	14.6	6.1	6.8	0.0	20.5	6.8	0.0	

TABLE 7.2.

THE HELPERS : RELATIONSHIP TO CARED-FOR PERSONS

%	<u>BATHING</u>		<u>WASHING</u>		<u>SHOES/ STOCKINGS</u>		<u>W.C.</u>		<u>FEEDING</u>		<u>CUTTING TOENAILS</u>	
	Elderly	Handi- capped	Elderly	Handi- capped	Elderly	Handi- capped	Elderly	Handi- capped	Elderly	Handi- capped	Elderly	Handi- capped
Father	0.0	53.8	0.0	73.7	0.0	69.2	0.0	75.0	0.0	57.1	0.0	43.8
Brother	10.5	7.7	11.1	5.3	11.1	3.8	12.5	0.0	20.0	14.3	0.0	9.4
Sister	0.0	19.2	11.1	15.8	11.1	23.1	12.5	16.7	0.0	28.6	3.2	15.6
Aunt	0.0	0.0	0.0	0.0	0.0	3.8	0.0	8.1	20.0	0.0	0.0	3.2
Son	15.8	0.0	22.2	0.0	22.0	0.0	12.5	0.0	0.0	0.0	20.7	0.0
Daughter	31.6	0.0	33.3	0.0	22.2	0.0	25.0	0.0	40.0	0.0	20.7	0.0
Daughter-in-law	5.3	0.0	11.1	0.0	11.1	0.0	0.0	0.0	0.0	0.0	3.4	0.0
Public health nurse or other official	26.3	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	20.7	6.3
	(n=19)	(n=26)	(n=9)	(n=19)	(n=9)	(n=26)	(n=8)	(n=12)	(n=5)	(n=7)	(n=29)	(n=32)

It can be noted from Table 7.1 that there is a good degree of independence on the part of the cared-for persons. Only a minority of 15 to 30 per cent need supervision or help with many of the tasks in either group. Bathing and cutting toenails cause greater difficulty. The elderly are less mobile than the handicapped and need more help to get about.

The carer is the person who gives most of the help with these personal tasks. Among the others who help, the father of the handicapped and the daughters of the elderly cared-for are the ones most often mentioned. Sisters, brothers and daughters-in-law come next. The public health nurse performs two specific tasks for the elderly, i.e., bathing and cutting toenails. But overall in the majority of the personal tasks, either the cared-for person performs independently or is helped by the carer alone.

Turning to household tasks the picture alters however. Table 7.3 outlines a set of household tasks and the help required and received on the part of the elderly. The carers of the handicapped were not included here.

TABLE 7.3: HOUSEHOLD TASKS AND HELP RECEIVED BY ELDERLY

Task %	<u>WHO HELPS?</u>				
	NO HELP NEEDED	Carer Alone	Carer and Others	Others in household	Others outside household
Cleaning house	12.4	76.1	1.8	3.5	0.9
Cooking	16.8	67.3	1.8	4.4	4.4
Washing dishes	17.0	67.0	2.7	11.6	2.7
Doing laundry	12.4	66.4	1.8	4.4	10.6
Making fires	16.2	61.3	1.8	12.6	1.8
Bringing in fuel	12.6	60.4	0.9	14.4	4.5
Gardening	3.2	48.5	0.9	26.9	14.0
Household repairs	1.9	32.4	0.0	33.3	26.7
Decorating	2.0	36.3	0.0	29.4	24.5
Shopping	4.5	74.1	1.8	8.0	5.4
Collecting pension	9.0	64.0	0.9	12.6	8.0
Budgeting	19.2	63.5	1.9	9.6	1.0

( n = 113 )

The cared-for are far more dependent in regard to household tasks than personal tasks and the carer is again the main source of help. But in many of these household tasks the carer receives help from others - more so than with personal tasks. Husbands and sons assume prominence here. For example, help with bringing in fuel came from sons in 46.2 per cent of cases, for gardening it was 52.0 per cent, 46 per cent for household repairs, 43.2 per cent for decoration, 57.6 per cent for shopping, 55.6 per cent

for collecting the pension. Perhaps this reflects the male role expectations within the culture? However, the sons helped with cooking in 23.5 per cent of cases, with cleaning in 25.0 per cent and with dish-washing in 31.3 per cent of cases; these activities would not be thought of as "men's work".

The contribution of spouses was examined in regard to the nature and extent of help given in Tables 7.4 and 7.5. The great majority of spouses do help but those of the carers of the handicapped seem to be more involved.

TABLE 7.4 : WHETHER SPOUSES HELP

<u>%</u>	<u>Elderly</u>	<u>Mentally Handicapped</u>
YES	72.2 (35)	91.0 (71)
NO	22.2 (12)	6.4 (5)
NO ANSWER	5.6 (3)	2.6 (2)
	(n = 54)	(n = 78)

(s = 0.0000)

The nature of care given by the spouses here was classified as follows in Table 7.5.

TABLE 7.5 : TYPE OF HELP PROVIDED BY SPOUSES

<u>%</u>	<u>Elderly</u>	<u>Handicapped</u>
Personal care	42.1 (16)	56.3 (40)
Minding	15.8 (6)	12.8 (9)
Outdoor activities	5.3 (2)	23.9 (17)
Other	36.8 (14)	7.0 (5)
	(n = 38)	(n = 71)

The carers then rated their spouses help as shown in Table 7.6.

TABLE 7.6 : SPOUSES HELP RATED

Rating %	Elderly	Mentally Handicapped
Essential	51.1 (24)	63.9 (46)
Very Important	21.3 (10)	16.7 (12)
Important	8.5 (4)	9.7 (7)
Not Very Important	8.5 (4)	8.3 (6)
Non Existent	10.6 (5)	1.4 (1)
	(n = 47 )	(n = 72)

The inconsistency between the responses on spouses help between Tables 7.4 and 7.6 may be due to the ambiguity of the "not very important" category in the ranking question. In fact, Table 7.5 shows that all 38 who said their spouse helped in the previous question were able to give details of the help given. Consequently 7.4 would seem to be a more reliable guide to the degree of spouses help.

Other members of the family both within and outside the house were said to help with personal care and outdoor activities. These included children, brothers, sisters and other relatives of the cared-for person. Table 7.7 outlines the contribution of relatives living within the household.

TABLE 7.7 : HELP FROM RELATIVES WITHIN HOUSEHOLD

%	<u>HELP GIVEN?</u>		<u>NATURE OF HELP</u>		
	Elderly	Handicapped		Elderly	Handi- capped
YES	82.1	95.2	MINDING	62.5	42.5
NO	9.5	4.8	HELP WITH ACTIVITIES	4.5	27.5
			PERSONAL CARE	0.0	10.0
	(n=48)	(n=68)		(n=48)	(n=68)

The help given by relatives who live outside the household is presented in Table 7.8.

TABLE 7.8 : HELP GIVEN BY RELATIVES LIVING OUTSIDE HOUSEHOLD

%	<u>HELP GIVEN?</u>		<u>NATURE OF HELP</u>		
	Elderly	Handicapped		Elderly	Handi- capped
YES	56.3	44.2	MINDING	53.6	53.8
NO	42.9	55.8	HELP WITH ACTIVITIES	0.0	25.0
NO ANSWER	0.9	0.0	PERSONAL CARE	7.1	8.3
	(n=112)	(n=86)	OTHER	33.3	20.0
				(n=112)	(n=86)

It would seem that by far the greatest part of personal caring comes from the carer and spouse in the case of the mentally handicapped cared-for persons and from the carer and others in the household in the case of the elderly. Using time diaries, Nissel and Bonnerjea<sup>1</sup> found in their study of care of the elderly within the family that

the wives spent, on average, two to three hours per day on essential care while husbands spent a mere eight minutes. In the absence of time diaries in this study it is impossible to determine the actual amount of time spent in caring by spouses. The help which comes from relatives outside the home is largely "minding" for both cared-for groups, with an element of taking the cared-for person out of doors for various activities in the case of the handicapped.

The rating given by carers to the help received from relatives living within and outside the household can be seen in Table 7.9 which allows comparison between the various relatives and neighbours who help. The help from relatives within the home is rated higher than that of family members outside the home. But both are rated highly showing that the carers appreciate every help received. Family loyalty may be at work here also. In most cases, carers were not demanding or critical in regard to lack of help from relatives outside the home or from neighbours.

Later, we will see that the presence of the cared-for person is generally thought to be a force for unity within the families. When the carers were asked if they thought that family members outside the home ought to be doing more to help, less than 10 per cent in each group felt they should.

TABLE 7.9 :

RATINGS GIVEN TO THE HELP OF RELATIVES AND NEIGHBOURS

	<u>CARERS OF ELDERLY</u>					<u>CARERS OF HANDICAPPED</u>			
	Spouse	Family members in house	Family members outside house	Neighbours	Public Health Nurse	Spouse	Family members in house	Family members outside house	Neighbour
ESSENTIAL	52.1	41.4	34.7	18.3	24.7	63.9	60.0	28.6	11.1
VERY IMPORTANT	21.3	32.8	32.0	39.0	24.7	16.7	32.9	47.6	33.3
IMPORTANT	8.5	15.5	13.3	22.0	15.5	9.7	7.1	19.0	27.8
NOT IMPORTANT	8.5	10.3	20.0	8.5	35.1	8.3	0.0	4.8	19.4
NON-EXISTENT	10.6	0.0	0.0	12.2	-	1.4	0.0	0.0	8.3

An interesting light was thrown on the help of relatives through responses to a question on how the carers coped with a crisis such as sudden illness of the cared-for person or an illness on their own part. After the doctor came spouses and relatives as helpers in crisis. Friends were lower down the scale and neighbours were not mentioned. Table 7.10 shows the sources of help in crises.

TABLE 7.10 : WHO HELPED CARER WITH CRISIS IN THE PAST AND TO WHOM WOULD THEY TURN IN A FUTURE CRISIS

%	<u>PAST CRISIS</u>		<u>FUTURE CRISIS</u>	
	Elderly	Handicapped	Elderly	Handicapped
Doctor	67.9	69.0	44.6	42.0
Spouse or Other relative	14.0	27.0	37.0	48.7
Friend	12.5	3.4	12.0	3.9
Other	5.4	0.0	6.5	5.3

When asked who actually helped the carer the last time she had to stay in bed for a whole day, husbands scored high (33.3 per cent) with daughters, sons, brothers, sisters and very occasionally neighbours coming to the rescue.

In a number of cases the carer made it clear that although she was ill she had to remain at her post.

*"Although I was in bed I was well enough to get up and give the old lady the injection which is vital for her diabetes. My husband got the meals, however."*

*"When I had Rebecca I was only in hospital about three days. I was sore and stiff but I had to come*

*straight home and start straight into looking after her and the other children including Michael, the handicapped child."*

*"It happened once when the children were at home and they helped to look after Grandma. I was well enough to give orders from the bed ;"*

Approximately 10 per cent of carers in both groups said they would have nobody on whom they could call in such a crisis.

Next came the help of neighbours. There was a significant difference between carers of the elderly and of the handicapped on this question as will be seen from Table 7.11.

TABLE 7.11 : WHETHER NEIGHBOURS HELP AND THE NATURE OF THE HELP GIVEN

	<u>DO NEIGHBOURS HELP?</u>		<u>NATURE OF HELP</u>	
	Elderly	Handicapped	Elderly	Handi- capped
%				
YES	56.6	32.9	MINDING	54.2      63.6
NO	42.9	67.1	OTHER	37.5      18.2
NO ANSWER	0.1	0.0	PERSONAL CARE	8.3      -
	( s = .0036 )		OUTDOOR ACTIVITIES	-      2.0

Neighbours help consists in "minding" - being present, chatting and generally giving friendship and moral support to both carer and cared-for persons. Hannan<sup>2</sup> pointed

out this function of neighbours in his study of small farmers in the South West of Ireland. The most important contribution which neighbours made and the one the farmers said they would miss most if they were to move from the area was "enduring day to day pleasurable conversations". The help of neighbours was also ranked next in importance to that of relatives outside the home as shown in Table 7.9 above. While their help is clearly seen as of less importance than that of relatives either within the household or outside, only 9.0 per cent of the carers of the elderly and 5.0 per cent of the carers of the handicapped felt that neighbours should be doing more. Neighbours are well regarded for their support even when they did not do much quantitatively. When they did give assistance they were very well regarded by the carers. The findings here on the carers' ranking of help received from family kin and neighbours coincides with Bulmer's summary of Abram's studies.<sup>3</sup> "Something like nine tenths of the care given to those who in various ways cannot fend for themselves in our society is given by spouses, parents, children and other kin."

It is probably true to say that caring for elderly or handicapped is viewed primarily as the proper task of the family. On the other hand, neighbours in Ireland may be like the Welsh neighbours, described by Wenger,<sup>4</sup> as loath to interfere when an elderly person has a family of his/her own in the area. Families do not

expect much more than interest, companionship and moral support from neighbours in the great majority of cases.

#### HELP FROM STATUTORY AND VOLUNTARY SERVICES

Table 7.12 sets out the position of the cared-for in relation to visits from the various statutory and voluntary groups.

TABLE 7.12 : WHETHER DIFFERENT OFFICIALS VISIT CARED-FOR PERSON

%	ELDERLY CARED-FOR		HANDICAPPED CARED-FOR	
	Yes	No	Yes	No
Doctor	76.6	23.4	11.5	88.5
Public health nurse	57.3	42.7	7.7	92.3
Social worker	0.0	100.0	23.4	76.6
Priest	94.4	5.6	5.1	94.9
Home help	12.3	87.7	0.0	100.0
Voluntary bodies	11.8	88.2	17.4	82.6

It is clear that the elderly receive more visits from almost all the statutory and voluntary representatives than the handicapped. This probably reflects the overall greater mobility and better health of the latter and, of course, it neglects to mention schools and training centres which play a very large part in the lives of carers and their handicapped cared-for.

The contrast between the priests' visits to the elderly and the handicapped is striking. I should have expected

at least an annual visit in the course of routine parish visitation.

The two most frequent visitors to the elderly are the public health nurse and the priest. With the carers of the handicapped the social worker who is employed by the Residential Home and paid by the Minister for Health is the most likely official person to call. Table 7.13 shows the frequency of the visits of the statutory and voluntary sector. As explained earlier, the social workers of the Health Boards work exclusively on family problems and consequently would not be involved with the elderly. The social worker who is employed by the residential home, St. Mary of the Angels, visits the families of those in the residential home on a regular basis to keep contact between home and institution.

The Home Help Service is confined to the elderly and almost exclusively to the elderly who live alone. It is only in the very recent past that families with children in this region receive a home help service when the mother is seriously ill and the children would otherwise have to be placed in residential care. The relative cost is the deciding factor here it seems.

The public health nurse is therefore the key statutory person in the care of the elderly and the priest for the voluntary sector. The public health nurse visited 57.3

TABLE 7.13

:

FREQUENCY OF PROFESSIONAL VISITS TO THE CARED-FOR PERSONS

%	<u>ELDERLY CARED-FOR</u>				<u>HANDICAPPED CARED-FOR</u>			
	Doctor	Public Health Nurse	Home Help	Priest	Doctor	Public Health Nurse	Social Worker	Priest
When sent for	58.0	24.8	11.5	2.0	100.0	87.5	52.8	88.9
Weekly	10.0	41.0	30.8	1.0	-	-	-	0.0
Monthly	25.0	24.2	50.0	86.7	-	-	8.3	0.0
Few times a year	7.0	10.0	7.7	10.2	-	12.5	38.9	11.1
n = actual number receiving any visit	100	61	26	98	51	32	36	27

per cent of the elderly in the study. In the previous study on Loneliness among the over 65s in the same region, 11.4 per cent received visits from the public health nurse.

Within the group visited in the present study, 41.0 per cent received a weekly visit, 26.2 per cent a monthly visit, 14.8 per cent said they sent for her when they were in need and 11 per cent were visited a few times per year. This compares with 18 per cent in Wenger's Welsh sample and 8 per cent of Hunt's English sample<sup>5</sup> who had received home visits from the district nurse within the previous six months of the interview.

Wenger found that those living alone in rural Wales were three times more likely to receive visits "despite the higher incidence of impaired health of those who live with others."<sup>6</sup>

The relative importance which the carers attached to the contribution of the public health nurse can be seen in Table 7.9. But there was a further dimension, namely, a contribution to the carer herself. 30 per cent of the carers felt that the public health nurse's visit helped them as well as the cared-for person. Moral support was the chief contribution together with some tips about personal care.

The most frequent services provided by the public health nurse were those of examining the patient, taking blood

pressure, doing dressings, doing blood and urine tests, giving injections, checking on medicines and cutting toenails. The next most frequent task was washing or bathing the patient.

After these services, importance was sometimes attached to the chat which the nurse had with the cared-for person; though not by all, since one or two felt that the nurse did little else apart from chatting! But a few stressed the moral support which the nurse's visit gave to the cared-for persons and two or three acknowledged the same for themselves. The visits were described in the following terms.

*"She comes and there's a general chat. My mother has a bunion problem and she dresses this for her."*

*"If Mary needed washing, she will wash her. She applies special ointment to the stump of her amputated leg and the nurse is excellent."*

*"She washes and dresses her and combs her hair and sees to all her personal needs."*

*"She takes her blood pressure, tests her urine and makes sure she is comfortable. She gives me sheets, paper sheets, and I have found these very helpful."*

*"She does nothing, only say, "hello, how are you?". She cuts her nails and brings her tablets when she wants them."*

*"She doesn't do anything. She just sits down on*

*the chair and chats half the day."*

*"I only saw the public health nurse once, and as far as I could see, all she did was take her blood pressure."*

*"She doesn't have to do much for him because he is pretty good himself. I suppose she just checks him up to make sure he is alright."*

*"She is a lovely person and Tim enjoys her visits. She sees after him well."*

*"She bathes her, cuts her nails, takes her blood pressure."*

*"She does nothing much, just chats. Since about two years ago when my mother hurt her leg, the public health nurse has visited regularly to wash and dress the injury. She talks to her mostly. As she is a cousin of my mother's, it has become very much a social visit."*

*"She gives him injections. She cheers him up a lot. She takes his blood pressure."*

*"She calls, but she always calls in the morning and Jerry doesn't want to see anybody before 12.00 noon at the earliest. She talks in the window to him and he doesn't get much satisfaction out of it."*

*"He tells her his complaints. She advises him about different things. She is very good and very kind. However, it is her support and the support of her visits which make me feel that there is somebody behind me. She listens to my complaints and rings the doctor if she thinks this is necessary and she cuts his toenails."*

*"She gives her a bed-bath, takes her pulse and blood pressure. She is great. She takes her out of bed and tries to get her to walk."*

*"I am able to share my own problems with the public health nurse and this is a great support to me."*

The public health nurse's help is perceived as important by the majority of the carers who experience her visits. She is important for the medical aid, the moral support and she also carries out a referral role to doctors and to the residential sector when this form of care is deemed necessary.

#### HOME HELPS

Only 12.3 per cent of the elderly have a home help; all are elderly who live alone. The home help is usually from within a few miles of the elderly person's home. The experience of the Health Board is that elderly people refuse to allow close neighbours to tidy or clean. The stranger is seen as less of a threat to privacy. The usual contribution is a weekly visit or a few times weekly at most. In two cases, there were full-time paid home helps who lived with the elderly persons.

#### VOLUNTARY BODIES

A surprisingly small minority of carers in either group

received direct help from voluntary bodies despite the strong tradition of this sector in Ireland. 11.8 per cent of carers had visits from voluntary bodies including the St. Vincent de Paul Society, the Legion of Mary, a Meals on Wheels Service and the Wheelchair Association. In the case of the carers of the handicapped only 17.8 per cent received any direct help from voluntary bodies. The most frequently mentioned were the Parents and Friends of the Handicapped (9.3 per cent), the Down's Syndrome Association (3.5 per cent), the Wheelchair Association (2.0 per cent), the Faith and Light (Jean Vanier) Movement (2.0 per cent) and the Brittle Bones Association (based in Scotland) (1.0 per cent).

The Parents and Friends Association have been instrumental in securing two schools for the handicapped and have set up two workshops in the area, but their work does not seem to touch the lives of the carers or the cared-for in a direct way and so got little mention.

#### THE PRIEST

Wenger<sup>7</sup> found that elderly people in North Wales received more visits from clergy than from any of the other professionals. She described the regular visits of clergymen of different denominations and, in particular, of the Non-Conformist ministers to the elderly in their homes and in hospital. She found that the clergy in North Wales were three times as likely to visit as the

clergy in Hunt's study.<sup>8</sup> 50 per cent of the elderly in North Wales had received a visit in the past six months.

The situation in Ireland resembles that of North Wales in that clergy visit the elderly regularly in their homes and also in hospital. The Catholic custom of bringing Communion once a month, on the first Friday, has ensured that the elderly who are housebound are visited by the priest on a regular basis.

In this study, 94.4 per cent of the carers said that the priest visited, 5.6 per cent said he did not. In marked contrast, only 5.1 per cent of the carers of the handicapped said the priest visited despite the fact that priests are expected to visit every home at least once per year. When questioned about the frequency of the priest's visit, the vast majority said that the priest came once a month. In the case of the elderly, 86.7 per cent said that the priest came once a month, 1 per cent said he came once a week, 2.0 per cent said he came when he was sent for and 10.2 per cent said he came a few times a year. It is clear that the monthly visit is the regular First Friday Call. When asked if they felt that the visit was important for the cared-for person, 94.4 per cent of the carers said they thought it was, 0.9 per cent thought it was not and 4.6 per cent were not sure. They were then asked to say

why they thought it was important. The most frequent answer was the "the old person looked forward to the priest's visit on the first Friday". They described, in a number of cases, how preparations were made and how the old person often saw the monthly visit as "the highlight of the month" for them. 30 per cent mentioned the fact that the elderly person looked forward very much to the First Friday Communion visit of the priest.

The second reason given was that "the old person was a religious kind of person", "a person with great faith", "a person who had always gone to Mass while they were able and now saw this as a substitute for attending Mass". 28 per cent gave this as the reason. Some people simply said that "the old person loves to see the priest coming", or "likes to receive Holy Communion". 20 per cent mentioned this as one of their reasons at least for the importance of the priest's visit to the old person. Then, 18 per cent mentioned the fact that the old person received either a moral boost or were made very happy or consoled by the visit of the priest. The carers seemed to see both the religious significance of receiving the Sacrament and also the social side of having a chat with the priest. There were three cases in which the carer felt that the reception of the Sacrament meant that the old person was prepared for death should it occur suddenly.

The carers gave their reasons in terms such as these:

"Mary is very religious. She likes meeting the priest every first Friday. It is one of the things she looks forward to every month."

"Because she always looks forward to it. It helps her a lot. It brings her out of herself."

"It's very important to every old person."

"He has a great chat with the priest and he'd keep him all day. He tells him about everything. He loves to meet the priest and feels better when he has Confession and Communion and when he gets his troubles off his chest."

"She would be very disappointed if he didn't call. This is the highlight of her life, to have Confession and Communion. She feels to happy when she gets the Holy Communion."

"He looks forward to it so much and he loves the priest and it does him great good. He is a man of great faith. He loves receiving the Blessed Sacrament."

"She always liked going to Mass and now when she cannot go, she loves to receive Holy Communion at home. The day before he comes she'll say to me, 'Tommy, have you the candle and holy water ready for the priest in the morning?' "

"She is a holy person. She likes receiving Holy Communion."

"He is a very religious man. He loves to receive the Sacraments."

"The Canon comes a few times a year and Denis

receives Confession and Communion. He still goes to Mass occasionally."

"Religion is very important to old people. She pretends she doesn't want the priest, but worries if he's five minutes late."

"She was very holy and was always praying and looks forward to the priest's visit."

"She was always a great person for Mass. While she was able to get about she was never late. She'd like him to come every morning if he could. She's an exceptionally holy person."

"Since he can't get to Mass, he likes to have the priest come to the house."

"All old people look forward to the first Friday. It pulls her up and helps her morale. It renews her interest in the house and in her appearance when the visit of the priest is due."

"It makes her day and she counts the days until he comes. She loves getting Holy Communion."

"She feels very happy when she expects him and after he's gone she's very happy too. She looks forward to it. It's a big occasion for her. She likes to see the priest even though she is not over religious."

"It's very comforting for my mother-in-law to have the priest visit her."

"We enjoy this first Friday. All three of us receive and it is lovely."

*"She is a very religious person and devotes most of her time to prayer. She looks forward to the priest's coming and feels very well afterwards."*

*"She looks forward to the day. It is a great interest for her, preparing the house and getting the candles ready."*

*"I think he really couldn't care less whether the priest comes or not."*

It is clear from these comments that the First Friday Communion Call has both a religious and social function in most cases for the cared-for persons. To a lesser extent, it helps the carer also.

Thirty three of the carers of the elderly said that they liked the priest's visit and personally looked forward to it. They felt that the coming of the priest and the bringing of the Communion were in themselves pleasant events and they liked them. Ten of them mentioned the fact that the visit of the priest gave them moral support. It showed that the Church was interested in them and in the sick. It gave the carer an opportunity of chatting with the priest and of being reassured of the importance of their task of caring. Four people mentioned that they received a "spiritual boost" from the visit. Four others mentioned the reassurance that, should the old person be taken suddenly, they would have received the Sacraments. It should be mentioned that the tradition here is that when somebody is taken

suddenly ill, the priest is sent for at the same time as the doctor, so that the Last Rites can be administered. However, the most common reaction from the carers was the effect the visit had on the old person. It was this which gave them the greatest satisfaction with the priest's visit. Seeing the old person happy and in good humour and obviously consoled gave the carer, in turn, reason to be happy and grateful. Thirty two of the carers of the elderly mentioned this.

Though the priest's visit causes some extra work for the carers in that they have to tidy up the house, prepare a table cloth and candles, and also the elderly person in many cases, nevertheless, when asked whether the First Friday visit created any difficulties or any extra work, only 3.7 per cent said it did, 96.3 per cent said that it did not. This showed an overall attitude to the priest's visit which was very positive indeed.

In summary, it would seem that the carers set great value on the help received from spouses, family members within and outside the home, neighbours and social services statutory and voluntary. From the actual amount of help reported one would be tempted to think that the carers over valued the help of others. This would be to omit the dimension of moral support and the reassurance that help would be available in a crisis. Family and community loyalty is a factor also as is the cultural set of expectations within which the carer

lives and which she largely accepts as "givens".

An interesting finding is what the carers thought would happen to the cared-for person if they were no longer available. The results are shown in Table 7.14.

TABLE 7.14 : IF THE CARER WERE NOT AVAILABLE  
ANY LONGER WHAT DID SHE SUPPOSE  
WOULD HAPPEN TO THE CARED-FOR PERSON

Who would look after Cared-for person?	% ELDERLY (n = 112)	% HANDICAPPED (n = 86 )
Other family member (excluding spouse)	40.5	32.5
Husband specifically mentioned as carer	7.5	31.3
Residential Home	37.7	25.5
Neighbour	3.7	0.0
Self-help, i.e., cared-for person could manage alone	3.7	0.0
Home Help (paid)	1.8	0.0
Could not bear to think of it	0.9	1.8
Don't know	0.9	2.3
Other	2.8	2.3

There was more reliance on family members, including spouse in the case of the carers of the handicapped, to continue the caring outside the residential sector. Neighbours did not count for very much when full-time caring was involved. Theirs is a very secondary role. The primary role is with the family.

NOTES

1. Nissel, M., and Bonnerjea, L., 1982, *"Family Care of the Handicapped Elderly : Who Pays?"*, Policies Studies Institute, London, p.4
2. Hannan, D., and Katsaiouni, L.A., 1977, *"Traditional Families? From Culturally Prescribed to Negotiated Roles in Farm Families"*, The Economic and Social Research Institute, Dublin, p.85.  
 The findings of this study indicate that a once thriving mutual aid system has declined to a residual level. Neighbours are not privy to secrets and confidences. They are never approached for financial loans. Their main function now is for conversation and exchange of news. But the farmers said they would miss their neighbours more than their relatives if they had to move to a new County.
3. Bulmer, M., 1986, *"Neighbours : The Work of Philip Abrams"*, Cambridge University Press, Cambridge.
4. Wenger, G.C., 1982, *Personal Communication*
5. Hunt, A., 1978, *"The elderly at home : a study of people aged sixty five and over living in the community in England in 1976"*, Social Survey Division, OPCS, (Unpublished tables)
6. Wenger, G.C., 1984, *"The Supportive Network"*, George Allen and Unwin, London, p.54
7. Wenger, G.C., 1984, *op.cit.*, p.63
8. Hunt, A., 1978, *op.cit.*, (OPCS, Unpublished tables)

CHAPTER 8DYNAMICS OF CARING

One of the most important parts of the questionnaire/ interview was an exploration with carers of the social costs and rewards of caring. The question of what motivates them and what keeps them going was examined, as were their fears for the future.

Since Motivation is a key issue in the dynamics of caring, I shall examine it first. We saw earlier that carers saw their task as "natural" in the context of family relationships and to a much lesser extent in the context of community relationships. The carers were asked how the task had fallen to them and their answers reflected a sense of family obligation which they seemed to accept without question in most cases.

They were therefore asked the direct question as to whether they assumed the caring role out of a sense of duty. 60 per cent in each group said they had. They then elaborated:

*"It is my duty, that's all"*

*"It is my duty to look after my own children surely"*

*"His father always felt that we should look after him"*

*"It's a mother's duty to look after her children"*

*"I have a responsibility to all my children including the handicapped child"*

*"Mary is my wife and I felt obliged to do my best to look after her"*

*"I felt it was my natural duty to look after my mother in her old age"*

*"I knew that my husband was very anxious that I would look after his mother"*

*"I should look after my own father, surely"*

*"It's bound to be my duty. You can't expect a neighbour to do it for you if you don't do it yourself"*

These replies acknowledge the duty to care for family members, elderly and handicapped, as a normal part of family life.

The next most common type of reply was that there was "really nobody else to do it". This shows that the carers see themselves as the last line of defence but they are not complaining too much. In fact, in a previous question, the vast majority did not feel there was anything unfair about the fact that they were left minding the child or the elderly person. They simply saw the caring task as falling to them in accordance with tradition and all round expectations.

*"There was no one else to look after her"*

*"She had nobody else but me left. 'Twas a foregone conclusion that I should look after her"*

"There was no other choice but to take charge"

"In my case it had to be; there was no one else to care for her"

"I felt nobody would care and love her as we did"

"I go to that townland every day and twice during the winter; nobody else calls to that old lady so I feel I have to do it"

"Well, all the rest of the family are in England"

"Sure, the poor man had nobody else after his wife dying"

"There was nobody else to look after her so I said as I was the youngest I'd try and keep the place together"

"The fact that he was here in the house when I came and who else could be expected to do the job"

"Yes, there was no one else there. If I didn't, who would?"

"I'm the only one she has in Caherciveen. She is my husband's mother and I would feel bad if I didn't do it"

Another frequent response was to appeal to family relationship as a sufficient explanation.

"He was my child"

"He was my child. I wanted to do the best for him"

"She was my daughter and I had to look after

*her and no more about it"*

*"Sure, you couldn't see your mother not looked after, could you?"*

*"He is my own"*

*"He was Sean's father and I became part of his family when I married and I cared a lot for him"*

*"I'm his wife and it's my duty"*

*"He is my neighbour. I am nearest to him, I'm only down the road. He was always a good neighbour"*

Another set of responses was to express a love of the cared-for person as the motive.

*"I love my child and I like minding him"*

*"I have cared for him because I love him"*

*"We have as much love for her as for the rest of them"*

*"Because she is my sister and I care for her very much"*

*"She is my wife and I love her and I feel it is a privilege to look after her while my own health holds out"*

A small number of people gave reasons which stemmed from their religious convictions. This was true in particular in the case of the carers of the handicapped.

"If God gave him to me it was to take care of him and not throw him away. Anyway, you could not throw away your own child no matter what kind they are. God gave him to us"

"God send him to us so we were bound to take care of him"

"He was my child, God sent him to me and I was bound to do what I did"

"I see it as my Christian duty to support a neighbour in need"

Some answers involved a mixture of the reasons given above, and occasionally, the carers of the elderly gave serial altruism as their motive.

"I feel I will be old myself some day and hope someone does the same for me"

"I am better able to do it than the rest because if I was in the same position I would like someone to do the same for me"

"He looked after me when I was young so it is only natural now that I would look after him when he is old"

"I felt I owed his mother this much because my mother-in-law was good and kind to me always"

"Well, I was always good to her, but she was such a good mother and she didn't have an easy life"

The various explanations given for feeling a sense of duty are given in Table 8.1.

TABLE 8.1 : SENSE OF DUTY ELABORATED UPON

	Number of times mentioned	
	CARERS OF ELDERLY	CARERS OF HANDICAPPED
Sense of duty re-stated	15	12
Close family relationship given as reason for caring: mother-child; brother, sister, wife, aunt, uncle	14	22
Nobody else available or willing to do it	12	7
Carer loves cared-for person or likes looking after him/her	4	5
Carers felt it was no trouble	9	6
Cared-for person is regarded as one of the family	3	4
Religious motives expressed	2	4
Carer speaks of reciprocal debt owed to parent because of being looked after as child	9	0
Unwillingness to send cared-for person to residential setting	4	4
Duty as good neighbour	2	0
Other	4	4
Unable to give reason	2	1

Since some tended to mention more than one reason the percentages are not given for each case. The empathy, affect and sense of duty which Abrams<sup>1</sup> identified as important factors are very much to the fore here.

So was reciprocity which he stressed even more. The reasons are very much family based.

When we examined whether the sense of duty was to the cared-for person or to someone else only 10 per cent of the carers of the elderly and 1.3 per cent of the carers of the handicapped said it was to someone else - to husbands in the case of wives who looked after husbands' parents for example.

The family was reported to be a stronger source of this sense of duty than religion. Table 8.2 shows that the choice was in favour of family among carers in both groups.

TABLE 8.2 : WHETHER RELIGION OR FAMILY WAS THE MORE IMPORTANT SOURCE OF THEIR SENSE OF DUTY

n = 178	%Carers of Elderly	%Carers of Handicapped
Family more important	35.3	60.5
Religion more important	24.5	7.9
Both equally important	40.2	31.6

(s = 0.010)

Family motives were significantly more frequent in the case of the carers of the handicapped. Perhaps the more frequent contact which the carers of the elderly had with their priests could explain this? Or, perhaps, the closer blood relationship on the part of the carers of the handicapped, mother-child most often, made the family the stronger force in this case.

The carers did not seem to be excessively motivated by

social control factors such as possible criticism from family, neighbours or clergy if they failed in this task. Table 8.3 gives the picture.

TABLE 8.3 :      WHETHER CARERS FELT THEY WOULD BE SEVERELY CRITICISED IF THEY FAILED TO CARRY OUT THEIR TASK

Severe criticism expected from: %	CARERS OF ELDERLY		CARERS OF HANDICAPPED	
	Yes	No	Yes	No
Family	37.3	62.7	47.1	52.9
Neighbours	38.1	61.9	38.6	61.4
Clergy	17.3	82.7	22.5	77.5

The neighbours do indeed exercise a considerable degree of influence as critics, almost as great as the family overall. But then in a community where everybody knows everybody else, the carers are naturally somewhat sensitive to neighbours' opinions, probably more so than than in an urban setting. In the earlier study<sup>2</sup> on Social Stigma, recipients of welfare payments felt that they suffered a great loss of face before neighbours who inevitably came to know of their situation. They experienced a much higher degree of embarrassment before neighbours than before family. The gossip of neighbours in rural Ireland has been a topic much written about by novelists, a good example being, *The Valley of the Squinting Windows* by Brinsley McNamara.

A final question, well on in the interview, probed the

carers' motives yet again. "If you were asked the crucial question, 'why do you do it and why do you continue to care when it becomes very difficult', how would you answer?" The earlier questions may have caused the carers to ponder on their motives, or the building up of rapport with the interviewer may have helped to overcome initial shyness, but they now began to bring expressions of love for the cared-for person to the fore. They also tended to give two or three reasons together, as for example, "*I do it because he is my father and I love him and there is no one else to do it*". These responses are outlined in Table 8.4.

TABLE 8.4 : WHY CARER CONTINUES WHEN IT BECOMES VERY DIFFICULT

Reasons given and number of times mentioned	Carers of Elderly	Carers of Handicapped
Love of cared-for person mentioned or feelings of special affection	24	34
Cared-for person is really no trouble	16	15
Sense of duty felt	18	12
Close blood relationship given	13	16
Carer enjoys the task and wants to continue	19	11
No one else to do it	3	3
No choice in the matter	3	3
Cared-for person's needs stressed	0	4
Other	5	5
Religious reasons given	3	2
Philosophic reasons given	3	3

What emerges here is a positive attitude over and above a sense of duty. There is a playing down of the difficulties, "no trouble", and an admission on the part of many that they enjoy the caring role despite its difficulties ....

*"Because I love him like nobody else"*

*"We all love Maura. We all look forward to the weekends when she comes home because we love her and want to care for her."*

*"She is my child and I don't want anyone else to care for her. I love her more than the rest. We love her and she is a child of God."*

*"Because he is adorable"*

*"She is very lovable. I feel that I will have her when all the others are gone. My only fear is what will happen when we are gone. Her brothers and sisters are mad about her."*

*"We love her and I couldn't put her in residential care as she wouldn't be happy there"*

*"Because I love her and we all love her and I miss her when she is away in the workshop during the week"*

*"I love her that much I wouldn't part with her"*

*"I feel he is my special child"*

*"She is my child. I love her. She is so affectionate"*

"She is my wife, I love her. It would be different if it were somebody else."

"Because I love my mother"

"I love her and I will miss her when she goes"

"Because I love her and because she needs me"

"I am very attached to the old man. He is one of the family. I get a sense of satisfaction from looking after him."

"I love my mother and all I want is to see her happy"

"Because I love my mother, that's why, and when she dies, I'll die myself too"

"I love my grandmother and I get a sense of fulfillment out of doing it. She's great crack. She's like one of our own (age group)."

"He is very close to me, he's a great companion. I am paying him for his goodness to me when I was young."

"I was always very fond of him. He was the only man in my life."

"She's my flesh and blood. There's a great bond between us."

"She is a sweet old lady who loves meeting people and enjoys company. I like her company too."

"I have cared for my mother and father all these

*years. I will be lost the day they leave me."*

There were similiar explanations in regard to the sense of duty such as, *"Well at this stage, a sense of obligation. That's why I keep going. She's my mother. My conscience wouldn't allow me to do otherwise."*

Others stressed the fact that their handicapped child or the elderly cared-for person was "one of the family" and was regarded as such and treated the same as any of the others. However, one quite different and interesting reason emerged, a neighbour who had rented the land of an old lady: *"Grazing, it is an economic arrangement; I get the grazing free, I save her turf and I keep a watchful eye to see that she is alright."*

The rewards of caring began to appear also in these responses, some insisting without prompting that it is really no trouble, others stating of their own accord that they enjoy the task.

The carers were asked a series of questions which might indicate the quality of their relationship with the cared-for persons. The responses are given in Table 8.5.

TABLE 8.5 :

WHETHER CARER WOULD DESCRIBE CARED-FOR PERSON AS :

	% CARERS OF ELDERLY (n = 107)		% CARERS OF HANDICAPPED (n = 86)		SIGNIFICANCE ON CHI SQUARE
	YES	NO	YES	NO	
	<u>YES</u>	<u>NO</u>	<u>YES</u>	<u>NO</u>	
A very good companion	83.2	16.8	94.2	5.8	0.0338
Very close to carer	86.0	14.0	100.0	0.0	0.0000
Someone carer likes to be with	88.7	11.3	98.8	1.2	0.0125
Someone carer looks forward to returning to	86.7	13.3	98.8	1.2	0.0045
Someone with whom carer gets on well	92.5	7.5	100.0	0.0	0.0260
Someone with whom carer can have a disagreement without falling out	92.6	7.4	96.5	3.5	0.3898
Someone who can often be very demanding	36.2	68.8	54.7	45.3	0.0160
Someone who is difficult to get through to	27.9	72.1	28.6	71.4	1.0000
Someone who is just not happy and cannot be cheered up	16.2	83.8	0.0	100.0	0.0003
Someone who one just could not please	7.6	92.4	3.5	96.5	0.3644
Someone who never shows any signs of thanks or appreciation	7.8	92.2	2.4	97.6	0.1818

The overall reaction is decidedly positive, showing a great loyalty. However, a substantial minority of the elderly are described as "often demanding" and "difficult to get through to" by the carers. Some of the handicapped cared-for are described as even more demanding. But there is no gainsaying the strong bond of love and affection which binds the carers and cared-for. It is slightly stronger for the handicapped.

There were "bad moods" on the part of the cared-for: 52.7 per cent for the elderly, 66.7 per cent for the handicapped. 30.9 per cent of the carers of the elderly lost patience with the cared-for as against 60.2 per cent in the case of the handicapped. The handicapped occasioned a significantly greater loss of patience. The bad moods were coped with in various ways such as ignoring them, coaxing, putting on music, going for drives and, most of all, the use of silence until the mood passed off. The carers of the handicapped felt they had to be firm by not yielding to screams or scenes.

What annoyed the carers of the handicapped about the cared-for was stubbornness, problems with toilet and personal cleanliness, aggressiveness towards the other children, a tendency to repeat questions and to demand attention on the part of the cared-for.

*"He refuses to do what I tell him. When he makes up his mind not to do something, he can be very*

*obstinate."*

*"He has to be brought to the toilet constantly"*

*"Her eyes and her nose are always wet. She always wants me there."*

*"He throws his clothes everywhere"*

*"She is a great little nagger"*

With the elderly it was personality clashes which created problems, but only in a minority of cases. Elderly were sometimes described as "impossible". Their propensity to "say the hurtful word", to be "cranky", to be "stubborn", to "spoil the grandchildren" and a wide range of other complaints were listed by a minority of carers.

The majority of both groups of carers felt that they were closer to the cared-for person now than they were at the beginning of the caring experience.

Table 8.6 shows the feeling here.

TABLE 8.6 :      WHETHER CARER AND CARED-FOR ARE  
CLOSER NOW THAN WHEN CARING BEGAN

%	Carers of Elderly	Carers of Handicapped
Closer now	62.2	50.2
Same degree of closeness	31.5	47.6
Less close now	3.6	1.2
Don't know	2.7	0.0

The cared-for persons shared confidences and worries with carers of the elderly in 78.6 per cent of cases and similiarly for the handicapped with 68.4 per cent sharing. Exactly 75 per cent of the elderly entrusted their financial affairs to their carers.

What the carers liked most about the caring task was the affection and appreciation shown by the cared-for person. This was mentioned 48 times in all.

Expressions of personal fulfillment and satisfaction were given 29 times. "Seeing the cared-for person happy" was mentioned 29 times. "Personal enjoyment of the task" was mentioned 27 times. The sense of having done one's duty, or fulfilled an obligation was given 8 times. Five stressed that caring was "really no trouble at all".

Some examples of what the carers of the handicapped liked most about their task:

*"She's very affectionate and lovable and always says 'thank you' "*

*"Her affection. She is like a five year old child"*

*"She appreciates everything. She is a very affectionate child."*

*"He is a pleasure. He is so loving and good-natured."*

*"Her affection, her company, the little things*

*she does and says, the things that make us laugh together"*

*"He is an adorable loving creature"*

*"I suppose I take pride in the fact that I am the most important person in her life"*

*"I love looking after my child. I love buying her clothes and shoes and have her looking nice."*

*"I feel I am doing something special"*

*"She has so much love to give. She is a very sympathetic child."*

*"I just love caring for him. He likes me to make a fuss of him. He is so affectionate."*

*"I get a great sense of pride and satisfaction when she achieves something"*

*"He is all we have left now and I love to see him coming home"*

*"Doing the best I can for my child, helping her to learn, to cope with life"*

*"I just like talking to her. She is a pleasure. She is so loving and good-natured."*

*"Getting all the love back, the satisfaction of it. That's very rewarding."*

Similiarly with carers of the elderly:

*"When he says how thankful he is and how happy he is"*

*"She is such good company and so appreciative"*

*"If I can do something to cheer him up it makes me feel good also"*

*"She is just like a grandmother, like one of the family"*

*"When I see him happy and comfortable and he always appreciates everything. It makes me happy too."*

*"He is good-natured and good humoured and no trouble"*

*"I know I am making life easier for her by doing various jobs for her"*

*"She is very kind and very appreciative. I am happy when I see her happy."*

*"She is a very grateful person and appreciates everything I do for her"*

*"It is my duty to do everything I can for her"*

*"I like to see him cared for and happy"*

*"She is very thankful and co-operative"*

*"I enjoy it"*

*"To see her warm, clean and content in a loving atmosphere"*

"Somebody must care for him. I think it is the least we might give him after a long life time in the family."

"I like being with him. I like chatting with him. He is always very cheerful."

"She is a very nice lady and was always very good to me when she had her health"

"He is a quiet man. He never bothered anyone in his life."

"We are great friends and I love to see him happy. He is my husband and we care very much for each other. We enjoy each other's company. I feel a great sense of fulfillment from doing this task."

"I find it a great privilege to look after her"

"I take no notice at all. She is no trouble at all. I feel very good when she says she is happy."

One or two expressed negative feelings:

"I don't like anything about it"

"There is nothing in particular I like about it except that she is my mother"

"I have no likes or dislikes about it"

These were a tiny minority. The majority were very positive.

The carers of the handicapped tended to mention the

affection of the cared-for person while the carers of the elderly stressed the satisfaction that they had from seeing the old person happy and content. The carers seemed to be motivated more by feelings than by abstract principles and so would contradict Dr. Samuel Johnson's<sup>3</sup> opinion on the superiority of principles over feelings. Recent British writers like Lewis and Meredith<sup>4</sup> and Ungerson<sup>5</sup> would tend to support Dr. Johnson, having found that women carers generally give a sense of duty and obligation as their main motives. Men, however, tended to emphasise affection and love.

Coming to what the carers disliked most, the responses fell into the following main types. Fifty nine of the carers claimed that there was nothing they particularly disliked. Twenty six mentioned the fact that they were tied down a great deal by the caring role, that they had to be there all the time as the cared-for person demanded constant attention. Six said that the cared-for person was demanding both because of his/her personality and in terms of time needed. Eleven mentioned problems of keeping the cared-for person clean and tidy and a few of these were specific, e.g., difficulties regarding toilet. Four carers of handicapped mentioned having to reprimand and correct as what they disliked most. Three mentioned losing their patience, three mentioned tiredness, one frustration, one loneliness, two the stigma and embarrassment of having a handicapped child.

One mentioned the physical problem of lifting the handicapped young person. One mentioned having to give injections. One mentioned the fact that the elderly showed no appreciation whatsoever for what was being done and three mentioned that what they disliked most about caring was when the cared-for person was suffering and they were unable to do anything about it.

What is surprising about this is that even when they were specifically asked to state something they disliked, fifty nine of the carers stated that there was nothing that they disliked. Only one, and she was the carer in the earlier question who said there was nothing she liked, said in this case that she "disliked everything" about the caring role. The general picture, once again, shows either a loyalty to the cared-for person or it may be a genuine feeling that they did not find caring particularly difficult.

Of course, the minority who mentioned that they were tied in, that their care had to be constant, keeps the costs side of the balance sheet before us.

*"He cannot be left out of sight. He has to be watched the whole time."*

*"I always felt a bit embarrassed and a bit out of place having a handicapped child"*

*"I have to keep constantly at her to keep herself tidy. I feel I am picking on her."*

"Keeping an eye on him all the time"

"Having to be available all the time to care for her"

"The fact that he has to be watched constantly"

"She can be aggressive at times. At this stage, I still have to take her out to the W.C. at night. It is upsetting to think that she will not have a normal full life. Keeping an eye on her all the time and worrying about her future."

"Being tied so much. It can be very boring at times."

"Being tied down, the feeling that I will always have somebody dependent on me. That is a worry always."

"The strain of it when I am with him too long"

"Sometimes if I want to do jobs and if there is no one around, I can't do the work as I have to keep an eye on him."

"I am tired changing him"

"Having to do such simple things for her"

"Why did it happen to me? I dislike the stigma attached to the condition of handicap."

"Seeing her suffer and not being able to talk with her and explain to her"

"It gets very monotonous and the old lady takes me for granted"

"Looking at my father now that he is blind, when I

*remember how he used to love to be out working and read a paper at night"*

*"Mopping up operations but I am becoming used to it. You need a strong stomach."*

*"The feeling of being tied and used. The old man's messing at the table, messing up the bathroom and the sleepless nights."*

*"She doesn't appreciate what I do for her"*

*"Being trapped in the house all the time and not being able to get out"*

*"Being stuck at home all the time"*

*"Everything. When I see her condition getting worse it makes me very unhappy."*

The carers felt best about their task "when he/she (the cared-for person) is happy". This was mentioned sixty seven times. The happiness of the cared-for person was in itself reward for the carers. There was a sense of satisfaction at seeing the cared-for person in good humour, in good health and well looked after. The carers of the handicapped were happiest when they saw some improvement in the handicapped, or when they began to do things for themselves, or showed independence or progress. Seventeen mentioned special times when they felt very close to the cared-for person. These included evening time, Christmas time or the time when the cared-for person returned

after being away at school or at the workshop. Others said that it was when the handicapped was well-behaved they felt best. Among the elderly sample, some mentioned an improvement in the old person's health or mood as being a morale boost for them also. Five of the carers mentioned signs of appreciation for what they were doing as the source of their greatest satisfaction. One or two were philosophic and regarded it as a job to be done. Feelings did not enter into it for these. Two people said that they never felt good about the caring role, one being the person who pronounced negatively twice already. (See Life Histories, Case No. 8). So the carers generally felt happiest when the cared-for persons were responding to their efforts.

*"When I see her looking happy and healthy looking"*

*"When he achieves something new. When I see some improvement, however small, it is a step up and a step in the right direction. I feel very good then."*

*"When I go to the workshop and see what he is capable of doing and see what all the other handicapped there are capable of doing, I feel I am part of something very different from ordinary workshops and I feel privileged."*

*"When there is one to one contact with my daughter, when she is sitting on my lap around bed-time. That is when I feel best."*

*"When I see her so happy and see how much joy little things bring to her"*

*"When I come back after being away for a while and she hasn't seen anybody for some time and she appears so glad to see me back"*

*"My job is very rewarding and I feel very good about it at all times. I get great pleasure out of caring for my father and seeing him happy."*

*"I always like doing it. I never feel different about it."*

*"I never feel good about it"*

The responses to these questions seem to me to be very positive with the exception of a small minority of negative feelings expressed. The vast majority seem to take satisfaction and experience a sense of fulfillment in the caring role. But the few who are dissatisfied or who get little from it are a most important group since they may well be near breaking point. It is these carers who should be identified by community services and given prompt support lest caring collapses and carer and cared-for need hospital or residential care thus in Moroney's<sup>6</sup> sense "rewarding them when they cease to care". Overall, however, 91.8 per cent of the carers of the elderly and 97.6 per cent of the carers of the handicapped said they get a sense of fulfillment from the task. This must be a very surprising figure in the light of the literature of caring generally.

But on the costs side, 20.7 per cent of the carers of the elderly and 27.4 per cent of the carers of the handicapped felt that their social life had suffered because of caring. Of these, 70 per cent said that these effects were "very serious" or "serious".

There was a strain on their marriages, attributed to caring, for 8.5 per cent of the carers of the elderly and for 23.1 per cent of the carers of the handicapped.

This leads to the question of whether the carers get regular breaks or not. It will be seen from Tables 8.7 and 8.8 that the carers of the handicapped leave home very seldom despite the fact that most of their cared-for go to schools and workshops.

TABLE 8.7 :     HOW OFTEN CARER LEAVES THE HOUSE

%	Carers of Elderly (n = 113)	Carers of Handicapped (n = 86)
Daily	38.0	23.2
Every few days	2.2	2.9
A few times a week	33.7	62.3
Once per week	25.0	11.6

TABLE 8.8 : BREAKS FOR CARERS

%	CARERS OF ELDERLY (n = 112)				CARERS OF HANDICAPPED (n = 85)			
	Yes	No	Rarely	Never	Yes	No	Rarely	Never
Away on own regularly for a day	62.5	10.7	16.1	10.7	52.9	8.2	27.1	11.8
Away on own for a night	18.6	15.9	12.4	36.3	23.3	11.6	32.6	25.6

A minority of 27.7 per cent of the carers of the elderly and 32.5 per cent of the carers of the handicapped said they would like to get out more often. Their reasons for not going out varied from lack of transport or lack of money to not wishing to upset the cared-for person or impose too much on a trusted helper.

*"I can't get someone reliable to look after her and it is not everybody she will stay with"*

*"It's not every place I can bring her. For example, if I bring her to the doctor's surgery she could upset the patients in the waiting-room and might also throw things about the waiting-room itself."*

*"I just haven't the means to go. Our car is not very road worthy and my husband won't take us."*

*"I am too busy and I don't have the money"*

*"It's not easy. It's placing a heavy burden on someone else. I feel I can't go out on account of John."*

"I couldn't go out very much if he'd cling to me and start screaming if I were leaving the house without him"

"I would be too worried about my aged mother-in-law to enjoy being out"

"I feel obliged to stay and look after Mary. I wouldn't trust her if I was out too long. Anyway, she would give out to me when I got back."

"I have too much responsibility at home"

"If I went out more often I think it would upset him. He is very dependent on me, so I cannot go out too often."

"We live far away in the mountain here and we don't have a car"

"I know the way he carries on when I go out, tormenting the family as to when I am coming back, so that I can have no enjoyment out of going out"

"I can't go to the pub, where I would like to go, because I have no way of going and no money for the drink. I'd have to ask someone to sit here all night while I'm out."

These replies came from 24.1 per cent of the two samples.

But 47 per cent of the carers of the elderly and 59.3 per cent of carers of the handicapped said that they could only stay away for a few hours without upsetting the cared-for persons. The frequency of holidays

away from home is given in Tables 8.9 and 8.10.

TABLE 8.9 : FREQUENCY OF HOLIDAYS FOR CARERS

%	Carers of Elderly	Carers of Handicapped	
Every year	13.6	13.1	
Most years	1.8	4.8	
Some years only	10.9	13.1	
Never	73.6	69.0	(n = 199)

TABLE 8.10 : LENGTH OF HOLIDAYS FOR CARERS

%	Carers of Elderly	Carers of Handicapped	
A few days only	39.3	12.5	
A week	46.4	54.2	
Two weeks	14.3	20.8	
More	0.0	12.5	(n = 52)

It should be noted that in Ireland the annual holiday is not the institution it is in Britain and the relatively small percentages who take holidays away from home may not be very different for the carers than it is for families generally.

The need to have somebody to look after the cared-for person when they are out is one of the greatest problems for carers. In the case of the handicapped, the fathers are the mainstay (64.3 per cent) followed by other family members. Only 1.4 per cent mention neighbours. With the elderly, family members do most also but

neighbours assist in 21.6 per cent of cases. Help from neighbours again seems to go much more to carers of the elderly than to those of the handicapped.

The effects, good and bad, of outings for the carers and their charges are reported in Table 8.11.

TABLE 8.11 : EFFECTS OF OUTINGS ON CARERS AND CARED-FOR

(n = 188) %	ELDERLY		HANDICAPPED	
	Carers	Cared-for	Carers	Cared-for
Feels better	83.3	27.9	92.4	22.0
Feels much the same	-	63.5	-	74.4
Feels neglected	-	8.6	-	3.6
It varies	16.7	-	7.6	-

The good effects on the carers and the absence of any great ill effects on the cared-for when left at home indicate that more breaks for the carers would be very beneficial. More frequent breaks are one of the important overall recommendations which the carers themselves make and I can readily endorse their view.

The majority of carers had at least one hobby, 79.1 per cent in the case of carers of the elderly and 73.3 per cent in the case of carers of the handicapped.

Reading was the most common, mentioned 40 times, knitting and sewing, 30 times, watching television, 21 times, gardening, 15 times. For smaller numbers there was rug-making, flower arranging, weaving - one woman used

her own spinning wheel - and crochet was mentioned twice. A few attended greyhound and horse racing, played golf or badminton or went to the pub with friends. Those who had pastimes and hobbies seemed to enjoy them very much.

The carers reported a considerable amount of emotional stress, tiredness and a sense of being trapped.

Serious fears for the future were common among carers of the handicapped. These feelings are shown in Table 8.12.

TABLE 8.12 : STRESSES FELT BY CARERS

%	CARERS OF ELDERLY			CARERS OF HANDICAPPED		
	Yes	No	Not Sure	Yes	No	Not sure
Suffers from:						
Loss of sleep	15.5	83.6	0.9	17.9	78.6	3.6
Exhaustion	26.4	71.8	1.8	34.9	60.2	4.8
Emotional strain	25.9	73.1	0.9	45.1	45.1	9.8
Worry about the future	28.7	70.4	0.9	72.9	22.4	4.7
Sense of being trapped	14.0	84.1	1.9	22.0	73.2	4.9

There are serious stresses for a sizable minority in both groups of carers. Particularly serious, in the case of the carers of the handicapped, are emotional strain and fears for the future. These were significantly greater for the carers of the handicapped than for those of the elderly. Similar findings were reported by Bayley<sup>7</sup> and more recently by Richardson and Ritchie.<sup>8</sup>

In the case of the carers of the handicapped, the main fear was what would happen to their cared-for when they had passed away or had become too old to continue. The long term future of the child was the source of their fear. This was mentioned 24 times. Next came more short term fears as to what would happen the child after he/she left school, whether a place could be got in a workshop, whether he/she could cope with life and become independent. Doubts were expressed as to whether other members of the family would be willing or able to take over or indeed whether it would be fair to expect them to do so. They had fears about their own health also. A few were philosophic and a few others trusted in God's providence.

*"I wonder how will she be cared for when I am gone"*

*"Who is going to mind him when I am too old?"*

*"I worry in case anything should happen to his father or myself. I wonder who is going to look after him when I am dead?"*

*"I wonder where will he go when I die and there is nobody to look after him? I wonder will he be looked after with love when I am gone?"*

*"If I don't outlive Niamh what is going to happen to her? If anything happened to her father or myself who would look after her then?"*

(See Life Histories, Case No. 68)

*"The biggest worry is Susan being put into a Home when we can no longer look after her"*

"I wonder if he will be able to look out for himself in life?"

"I wonder if she will be able to look after herself?"

"I wonder if he will be able to cope with life and I hope that he won't get worse"

"I am always afraid that she will not be independent enough to cope in life"

"I wonder what will happen to Michael as he gets older? I wonder if he will be able to work and look after himself?"

"I worry a great deal about her. I worry about what will happen when she grows up and becomes a young woman."

"I am not worried for myself but I am very worried for Jimmy and for his future"

"Since my child has no brothers or sisters, will there be anyone to look after Patrick?"

"I wonder if one of his sisters would look after him when I am no longer available?"

"My greatest fear is that there won't be anyone to look after him"

"I take every day as it comes and do not allow fears to come into my mind. I leave all my worries in God's hands. He looks after them all."

"I put my trust in God. God has been very good to me so far. I know He will continue to be."

*"I fear that I may not be able to carry on for long more. I have great fears that Martin might become ill and that I might have to part with him."*

These fears and general uncertainty about the future on the part of parents were reported as follows by Bayley.<sup>9</sup> "Anxiety about the future pervaded the life of most if not all of these families. If they could be given some knowledge that their subnormal would be looked after in a way that would satisfy them, a great load would be lifted from them."

The carers of the elderly were not as prone to such fears but some did have worries. Perhaps most of them take for granted that they will outlive the cared-for persons. Their answers about the future tended to be philosophic - 22 of the 60 responses were of this kind, "I take every day in itself", "When the Lord calls my mother I'll be resigned to it", "As long as I can get about and have my health I am not afraid of the future". But a number had real fears concerning the future care of the elderly person.

*"My greatest fear is that of getting stuck with Hannah for the rest of my life as she is a very difficult person"*

*"My greatest fear is the fear of being stuck here for the rest of my life"*

*"My greatest fear is that of having a nervous*

*breakdown"*

*"If she were to lose her senses and if she became very troublesome, I would then have to put her into a hospital for good and I think that would upset me very much"*

*"I worry about how I would cope if she became senile and totally dependent on me for everything"*

*"I have no future"*

More than 90 per cent of the carers felt that they were naturally good humoured and less than 2 per cent felt that they were less so now than when they took on the caring task. Only 14.4 per cent of the carers of the elderly and 26.6 per cent of the carers of the handicapped felt that caring had changed them. The changes were not always negative in their view. But Table 8.13 details their perception of a number of the changes.

TABLE 8.13 : CHANGES PERCEIVED BY CARER AS A RESULT OF CARING

Results of caring:	CARERS OF ELDERLY			CARERS OF HANDICAPPED		
	More	Less	About the same	More	Less	About the same
Irritable	9.0	16.2	74.8	9.6	12.3	78.1
Patient	93.7	5.1	1.1	90.3	9.7	0.0

The perception that caring had made them more patient is an interesting finding. It came up again when the carers were asked how they had benefited from caring and what

caring had taught them. 78.9 per cent of the carers of the elderly felt they had benefited personally from the experience while 86.7 per cent of the carers of the handicapped felt similarly. On the question of whether contact with the cared-for persons had taught them anything, 69.4 per cent of carers of the elderly and 82.7 per cent of carers of the handicapped felt it had. The positive change or benefit mentioned most often was that caring had made them "more patient and understanding". However, we must not forget that in an earlier question as to whether they sometimes lost their patience with the cared-for person, 30 per cent of the carers of the elderly and 60 per cent of the carers of the handicapped said they did. Among the latter, 16.5 per cent had lost their tempers a lot, 44.7 per cent had sometimes lost their tempers with the cared-for persons over the past weeks. A further intriguing twist is that the male carers were slightly more likely to attribute the virtue of patience to themselves than were the females. And the male carers, without a single exception, regarded themselves as "naturally good humoured"! Some examples of how the carers felt they had changed because of their caring role:

*"It has made me a more thoughtful person, much less material in my outlook"*

*"It made me more open to other peoples troubles and less self-centred. It has made me grow for*

*the better and all growth is good. It has given me a chance to live out love joy, and peace in my life."*

*"I am more outgoing now than I used to be"*

*"I think it has enriched my life"*

On the negative side:

*"Sometimes I get worn out from it all"*

*"My child is a big responsibility and she depresses me at times. I would say I am more nervous now and I suffer a great deal from anxiety. It has made me more anxious and worried sometimes."*

*"I get fed up and upset at times"*

*"I can't call my life my own anymore"*

*"It is tiring. It has made me more serious. I was very light-hearted when I was young."*

*"It has made me seem much older than what I am"*

*"It has made me very old but it has not changed my personality"*

*"It has begun to get me down. I feel cranky and even the other children are now getting on my nerves."*

*"I feel that I have missed out on a lot of my life and that I look years older than I am"*

*"I am not as outgoing as I used to be"*

*"It has made me very bitter and resentful"*

*"I am a very embittered person. I used to love my own way of life and I no longer have any life of my own."*

There was a feeling among some of the carers that they tired more easily now than when they first began their task. A sense of isolation was also reported by some as shown in Table 8.14.

TABLE 8.14 : TIREDFNESS AND OTHER FEELINGS  
AMONG THE CARERS

%	CARERS OF ELDERLY			CARERS OF HANDICAPPED		
	Yes	No	Not Sure	Yes	No	Not Sure
Carers tires more easily now	46.4	50.9	2.7	68.1	27.8	4.2
Sometimes feels very much alone and isolated	16.2	82.9	0.9	23.3	76.7	0.0

The admission to feeling tired more easily could be indicative of a good deal of physical and emotional stress for the carer.

Both loneliness and boredom were reported also. The standard question on loneliness showed a relatively high incidence while a lower degree of boredom was also expressed as shown in Table 8.15.

TABLE 8.15 :      LONELINESS AND BOREDOM  
AMONG THE CARERS

%	CARERS OF ELDERLY					CARERS OF HANDICAPPED				
	Yes	No	Often	Some- times	Rarely/ Never	Yes	No	Often	Some- times	Rarely/ Never
Lonely	24.1	76.9	21.4	60.7	17.9	39.5	60.5	5.7	77.1	19.1
Bored	-	-	10.8	11.7	77.5	-	-	4.1	6.8	89.0

Among the elderly in the previous study the degree of boredom was much greater.<sup>10</sup> The carers of the handicapped tended to report loneliness more often and less boredom than the carers of the elderly. Those who said they felt isolated and alone felt this way chiefly because they were so tied down. Sometimes even when they were out they were anxious about the elderly person. Others saw their isolation as stemming from lack of confidants. Others again lacked a telephone or were living in isolated areas. A deserted wife in a rural area with other children as well as her handicapped son with no telephone, no public transport and living on a Deserted Wife's Allowance, is one example. Others:

*"I have to be there all the time, all days"*

*"She needs constant care and I am not free to go and come when I like"*

*"I live in an isolated area with very few neighbours. I feel a bit depressed at times. It is a great responsibility and it takes up an awful lot of my time."*

"I am living in a rural area. We are far away from the town, from the hospitals, from the doctors and so on."

"I am always tied down. When she is out with me I have to keep an eye on her all the time and that means I feel tensed most of the time."

"At times I feel cut off because I have to stay in such a lot"

"I don't discuss my troubles with anybody except my immediate family and close friends. There is no one with whom I can discuss Elaine as there is no information available about her particular disease."

"Because I am here always. I am here from morning till night. I am alone in the house with Pat. No one ever calls. I am responsible for everything that happens in the house."

"At times I feel trapped. I can't have anyone in to talk to. I feel uncomfortable with them because Jim, my father-in-law, doesn't want them around the place. I just can't stir and when I go out I have to rush back when all the other people are staying on. I feel my friends have lost touch with me as I am not free to go out and join them."

"I wouldn't be living here if I hadn't to look after my mother"

"There is no comfort going anywhere. You are always worried about him. I wish I was miles away from here."

The carers were asked to identify the greatest need of somebody in their position. The five main needs reported were (i) lack of companionship, by which they meant someone in whom the carer could confide and know she was understood, (ii) family support, both emotional and practical - the need for appreciation from other family members was felt by others, (iii) regular breaks for the carer, (iv) patience as vital to caring, (v) good health for the carer. Help from neighbours, ownership of a motor car, a telephone were mentioned by a few. Four or five mentioned money as their greatest need. Two were anxious to find a job for the cared-for person. Table 8.16 outlines these responses.

TABLE 8.16 : WHAT CARERS CONSIDER TO BE THE GREATEST NEED OF SOMEONE IN THEIR POSITION

Greatest need:	CARERS OF ELDERLY	CARERS OF HANDICAPPED
	Times mentioned	Times mentioned
Companionship/visits/company	23	22
A break	13	11
Help and support from family	21	10
Help from neighbours	2	5
Patience	3	9
Good health	2	5
Financial help from State	5	1
A job for cared-for person	-	2
Residential care for cared-for person	-	4
Home help	-	2
No need exists	8	1

"Companionship. Someone to talk over and understand the problem."

"Someone to talk to who is interested in Patrick"

"Friends and family. People to talk to and who would take him places because they wanted to not because they had to."

"Having a break now and then"

"Someone who understands my situation and could give me a break now and then"

"Company. Having someone to talk to."

"The start was the hardest and I often feel that if only I had someone to talk to then, it would have helped me greatly."

"To have someone reliable who would take the child out for periods"

"Plenty of patience and buckets of energy, good health and, above all, a sense of humour"

"To know that you are doing what is best for the old person"

"The little bit of company. It is nice to have somebody pleasant calling in."

When the carers were asked to specify the first thing they would do to support a friend in their situation, they confirmed the priority they gave to moral support and friendship. The responses are shown in Table 8.17.

TABLE 8.17 : THE FIRST THING CARERS WOULD DO TO HELP AND SUPPORT A FRIEND IN HIS/HER SITUATION

Suggested forms of help	CARERS OF ELDERLY	CARERS OF HANDICAPPED
	Times mentioned	Times mentioned
Visit, talk, give moral support	46	37
Mind child/old person for a time	9	19
Give carer a break	17	10
Would help in ways not specified, "anything I could" etc.	23	10
Would help in practical ways with housework, transport, shopping	11	2
Would give financial help	2	2
Would recommend residential care for cared-for person	-	3
Take carer out for a meal occasionally	1	0
Other	4	0
	(n = 117)	(n = 86)

The carers mentioned a number of times that caring had made them more patient, more understanding and less concerned with material things. The great majority felt that they had personally benefited from it. 78.9 per cent of carers of the elderly and 84.7 per cent of carers of the handicapped felt this way. An overall sense of satisfaction and fulfillment from their role was mentioned 66 times. A second response was that caring had made them "more understanding and tolerant" as persons. This was mentioned 27 times. Patience was mentioned 15 times. That they had "become better

people" was stated 10 times and "better Christians" five times. Nine people said it had caused them to appreciate their own health. All in all this showed that the majority saw their role in a positive light, one which, though difficult at times, had taught them much and had helped them to grow in ways in which they might not otherwise have done.

Carers of the handicapped:

*"It has given me a sense of fulfillment. It has given me more understanding for the handicapped."*

*"It has made me more thoughtful towards others"*

*"It has made me more thoughtful to older people. I feel for them. It is very important to be nice to people."*

*"It makes me appreciate my family, the fact that they are alright and in good health. I take great pleasure in the fact that none of my grandchildren are handicapped."*

*"You don't take half the things for granted. You are sensitive to other peoples feelings and more aware."*

*"It makes you a lot more tolerant"*

*"I have become more patient"*

*"I now have a different understanding of peoples problems"*

*"It is fulfilling"*

*"I am happy that I have looked after my handicapped"*

child all these years and I am glad that I never had to put her in a Home."

"It is rewarding. It has made me more patient and understanding."

"It is great to see that she has improved so much"

"It has definitely made me a better person. I feel Brian has paid us back in his own way."

"It has taught me to have more time for others and to realise that there is more to life than good times and a good social life. It has taught me that there are a lot of people with a lot of problems that I wouldn't have known about otherwise."

"It has made me more caring. It brings me down to earth."

"It's hard to explain but it's like a vocation for me"

"I'm not fussy about small things as long as Margaret is alright. She has made my life worthwhile. I am not as selfish as I used to be. I find that I am more considerate towards others. I am no longer as engrossed in myself as I used to be. There is a very close bond between us. I feel very close to her. I often think that if I had no one to care for my life would be aimless."

"Sean's handicap was badly needed in this house. It has made all of us more caring. It has given me a new purpose in life."

"I am not as bothered about material things as I used to be. I know that God is present in him and that I am doing something for the love of

God when I am taking care of him. It has made me less selfish and I no longer dwell on my own fears and phobias as I once used."

#### Carers of the elderly:

"It's good for myself to have to consider an old person and their needs. I feel that I will be rewarded in the future life for having looked after my parents in their old age. It has helped me to be grateful for my own good health although I sometimes suffer a little from my chest."

"My mother-in-law has lived a good long life. It is good to hear her talking about her life. I have gained a lot of help from her experience when it comes to looking after my own children. I am very thankful that the rest of the family, especially our children, are healthy. I understand old people better now and how they sometimes feel they are a burden and feel they may not be wanted. I have got more practical as a result of looking after her. Although I am moving on in years myself, I thank God for my own health and that I don't have the pains that my husband suffers from continually."

"It has been a great education for me. I now appreciate the needs of old people. It has made me more tolerant and more patient with people, old and young. I'd like somebody to do it for me if I ever reach her age. She cheers me up when I am down and out rather than vice versa. It has done a lot for my children. It has made them understand about old age. I believe it helps them and will do so in the future."

"It keeps me busy and happy. I would find the time very long if I didn't have him to look after."

"I enjoy it. I think it's great example too for my children to see me doing it."

"I have done a lot for old people specially neighbours, and have received no material benefits from it. I have received spiritual benefits I hope and, perhaps, it will do me good when I go to the other side."

"It makes you more understanding of the needs of old people and of the people who are caring for them."

"I feel good to be able to do it myself and not to be under an obligation to anybody else to do it for me"

"It is a great consolation to me to think that my mother was so happy in her last years and I feel I will have luck for looking after her"

"It has made me a stronger person, more sensitive to other people"

"It gives me something to do now that I am retired myself. It fills the day for me this way when I have someone to look after."

"Most people are very happy with what I do, especially my ageing father. I hope I will always continue to do something in the care of the elderly in my family or locality."

It is difficult not to be impressed by the spirit of self

sacrifice of the carers. But it is not all one way traffic. They receive a great deal too from the cared-for persons. The carers acknowledge that they have learned a good deal from the cared-for persons including valuable insights into the things which really matter in life. Jean Vanier<sup>11</sup> and Craig<sup>12</sup> have highlighted the ability of the mentally handicapped to recall us to the truth that man's need to love and be loved is more basic than the need for money, material things, pleasure or power. The phrase of St. Francis' prayer, "It is in giving that we receive", comes to mind as indeed does Richard Titmuss's<sup>13</sup> celebration of altruism in *"The Gift Relationship"* even though the exchange here is between relatives and not strangers, as in blood donations.

The carers expressed a profound spirit of altruism or love when they specified what their caring experience had taught them.

*"It is an eye-opener. Otherwise I wouldn't know what handicap was like. You have to experience things like this to understand them."*

*"That there is more to life than a good time. A lot of people have problems that we know nothing about."*

*"That no case is hopeless. That where you least expect a return, that's where you will find it. Annie is now my biggest consolation, though in the beginning, after she was born handicapped,*

*she caused me so much trouble, so much worry, so many sleepless nights. She was a source of great unhappiness then and now she is my greatest source of happiness."*

*(See Life Histories, Case No. 82)*

*"People should be a lot more content with what they have. It has given me social contact with other parents of handicapped children and this has widened my knowledge greatly. I now appreciate even more the fact that my other children are normal."*

*"It has taught me a lesson, to thank God for my other normal children. It has taught me that because I have a handicapped child I will never be alone in life. Handicapped children are very loving and it has taught me to understand the problems of other unfortunate people. It has taught me that I wasn't the only one, that handicapped people can lead a normal life in their own way too."*

*"Even though I am a teacher I had no understanding whatever of children with defects until my own daughter was born"*

*"That handicapped people are real people with feelings and love and they are God's own children and when I am with him I am very close to God also"*

*"It has made me more understanding of a handicapped child and more appreciative of my healthy children"*

*"It has made me patient, understanding and it has made me feel humble"*

*"It has made all of us much closer as a family"*

*"It makes you a different type of person. It makes you look at life in a completely different way."*

*"It has helped me to see God in everyone even in the weakest of His creatures"*

These came from the carers of the handicapped. Now some of the responses of the carers of the elderly:

*"Her qualities of holiness, patience and concern for other people have taught me to practice these qualities in my own life"*

*"It has taught me that time passes quickly and we will all be old one day and be helpless and it may happen even before we know it"*

*"It has taught me how dependent old people are on younger people. It has also taught me the dignity of old age."*

*"It has taught me to be thankful for my own strength and to be able to look after my mother"*

*"The experience has made me much less selfish. It has helped me realise that there are people in the world less well off than myself."*

*"She's an influence on me all the time. She has taught me everything I know. It would make you ashamed to think of what old people like her have been able to do in their struggle through very difficult times in the past"*

*"She has taught me a great deal about crochet, knitting and so on"*

"It has made me aware of the fact that we can take our health too much for granted. We should be grateful for being healthy."

"It has taught me how to love and respect the elderly. It has taught me to be more understanding, kind and compassionate towards old people and towards everyone else as well."

"It has taught me that nervous conditions, and especially depression, are very painful ones and that you have to have great patience with the elderly, especially when they have nervous disorders"

"It has led me to hope that I won't live to be too old and that my daughter won't have to look after me as long as I am looking after her grandmother"

"It has taught me that the world is a cruel place"

"She has taught me about the Cross. She has shown me how to accept and carry a cross. Her example encourages me in my life."

"It has taught me that many things happen as we go through life and we never know what is in store for us from one day to the next"

"Her devotion to her religion and to prayer has helped me down the years and is an example to me"

The literature on caring has tended to stress the costs of caring and to neglect to take adequate account of the rewards. Up to this point, the rewards and

satisfactions of caring would seem to outweigh the costs in this study. While the negative side was overstressed in earlier literature the balance has begun to be adjusted in recent times by such people as Baldwin and Glendenning<sup>14</sup> who conclude that the compensations and rewards of caring are substantial, though they do not go on to outline them in very great detail or give them their due weight in my opinion. Vincent<sup>15</sup>, commenting on this recent trend, concluded, "until recently there was a tendency in the literature to emphasise the costs of caring to individual women, to the family as a whole and to siblings ... More recent accounts have attempted to look at the totality of the experience of the carers and they have looked also at the benefits derived from caring".

However, the very recent work of Lewis and Meredith (1988) and of Ungerson (1988) while noting the rewards, tend to play them down or even explain them away. Consequently the hopes raised by Vincent have not been realised to any great extent, so far at any rate.

Lewis and Meredith<sup>16</sup> concluded that despite the bitterness felt by caring daughters who had cared for their mothers and the sense of lost opportunities, there was definitely a positive side also: "The fact remains that all but three respondents expressed some

positive feelings about having cared despite, in many cases, a heavy burden or long period of care. A majority expressed a sense of achievement that the mothers had not to leave their own home ...". Even in cases where the caring had been extremely difficult in all its aspects, all but a few still felt positively about having done the right thing. The rewards reported here after the caring had ended do not go beyond a satisfied sense of duty on the part of the carers. They do acknowledge however that, "positive feelings about caring are often derived not only from abstract satisfaction at obeying the injunction to care, but from the reality of the caring experience, and, in particular, from companionship, emotional security and appreciation it brings the carer". They stop short of acknowledging that there is any love or joy in the experience, despite the fact that it is mothers and daughters whom one would have expected to be very close. In fact, they stress, "One thing is clear, the idea of caring as a simple act of altruism on the part of one family member out of love for another, has little basis in reality".<sup>17</sup>

Ungerson<sup>18</sup> was taken somewhat by surprise at finding "a handful of women and, stretching the point somewhat, three of the men who experienced joy in their caring task. During this research I have been struck by two different kinds of carer ... those for whom caring

was truly grim, and those for whom it seemed to bestow a certain satisfaction, even in one or two cases, an extraordinary kind of joy. I could not make sense of this at all except in the cases of the joyful ones, to think generously in terms of genuine saintliness, or less sanguinely and much more arrogantly in terms of false consciousness". Although this study is a qualitative one, it is worth noting in passing that the two women and three men who comprise Ungerson's five "joyful mysteries" make up 25 per cent of her sample. One wonders how clear evidence can be played down and explained away. Further light is thrown on this through a case commented upon by Ungerson. A carer is being interviewed. "I love him so much that I won't let him be taken away." When "pressed further" she said, "I just think it's my duty. I'm a Lancashire lass; and Lancashire people are like that". Ungerson comments, "In effect she was indicating the power of ideology. Within a social science frame of reference it would be appropriate to describe Mrs. Fisher's sense of duty as deriving from a set of normative obligations which themselves derive from a set of gender-related norms".<sup>19</sup> Ungerson's<sup>20</sup> own bias is stated clearly at the beginning of her book, "The book that follows is rooted in the women's movement and my own biography, and watered and fed by feminist academic friends and colleagues and last but not least by the Economic and Social Research

Council". The power of ideology indeed !

It remains to be seen therefore whether future studies will acknowledge the rewards to carers. In the meantime, to remain with the idiom of labour and love, the attitude of carers in the present study could be summed up in Shakespeare's<sup>21</sup> words, "the labour we delight in physics pain".

NOTES

1. Abrams, P., 1977, "Community Care: Some Research Problems and Priorities", *Policy and Politics*, Vol.6 No.2, p.129
  
2. Clifford, D., 1975, "The Public the Client and the Social Services", *Social Studies*, Maynooth, 69 per cent felt loss of face before neighbours compared with 24 per cent before family when it became known that they were receiving benefits.
  
3. Boswell, J., 1791, "*The Life of Samuel Johnson*", Penguin Edition, Penguin Books, p.298  
 Boswell: "I believe natural affection, of which we hear so much, is very small"  
 Johnson: "Sir, natural affection is nothing; but affection from principle and established duty is sometimes wonderfully strong"
  
4. Lewis, J., and Meredith, B., 1988, "*Daughters Who Care*", Routledge, London, p.30  
 "On the whole respondents talked more about ties of obligation based primarily on notions of reciprocity than they did about affection, although there is a sense in which for the vast majority the fulfilling of obligations was predicated on affection"
  
5. Ungerson, C., 1988, "*Policy is Personal: Sex, Gender and Care*", Tavistock Publications, London, p.86  
 "... on the whole men used the language regarded as the language of marriage - that of love - while the women, even in two cases the women who were caring for their husbands, used the language of duty." However, she admits that, "some at least of the carers felt a strong loving basis to the caring they did".
  
6. Moroney, R.M., 1976, "*The Family and the State*", Longman, London, Ch.5

7. Bayley, M., 1973, *"Mental Handicap and Community Care"*, Routledge and Kegan Paul, London
8. Richardson, A., and Ritchie, J., 1986, *"Making the Break"*, King Edward's Hospital Fund for London, Holden Street Press, London.
9. Bayley, M., 1973, op.cit., p.261
10. Clifford, D., 1978, *"Kerry Diocesan Study on Loneliness"*, (unpublished)  
36 per cent of the over 65s reported that they were often bored
11. Vanier, Jean, 1985, *"Man and Woman He Made Them"*, Darton Longman and Todd, London, p.172  
" Very often people look upon L'Arche as if we are completely mad ... We consider those whom society devalues as valuable and capable of awakening what is most precious in the human being - the heart, generosity, the dynamism of love. They invite us to put our intelligence at the service of love. They have the capacity to heal others by calling them to unify within themselves their deep emotions, their capacity for love and their reason. Thus they can become sources of life."
12. Craig, Mary, 1979, *"Blessings"*, Hodder and Stoughton, Sevenoaks, Kent
13. Titmuss, R.M., 1970, *"The Gift Relationship"*, George Allen and Unwin, London
14. Baldwin, S., and Glendenning, G., 1983, "Employment Women and their disabled children", in Finch, J., and Groves, D., (eds.), 1983, *"A Labour of Love"*, Routledge and Kegan Paul, London  
" It would be wrong however to overlook the fact that care of a dependent child has its own compensations, and that many women with severely disabled children derive substantial rewards from their specialised task. These pleasures and satisfactions, rooted

in feelings of love and protectiveness, are reinforced by 'public opinion' and by the ideological values attached to motherhood and the family by contemporary social welfare institutions and practices." (Ch.3, p.56)

15. Vincent, J., 1987, "Carers Survey", Loughborough University, (*unpublished*)
16. Lewis, J., and Meredith, B., 1988, *op.cit.*, pp.151-153
17. Lewis, J., and Meredith, B., 1988, *op.cit.*, p.30
18. Ungerson, C., 1988, *op.cit.*, pp.144-146
19. Ungerson, C., 1988, *op.cit.*, p.89
20. Ungerson, C., 1988, *op.cit.*, p.16
21. Shakespeare, W., "*Macbeth*", Act 11, Scene 111

CHAPTER 9ATTITUDES TO MONEY, WORK, WOMEN VERSUS MEN AND THE FUTURE

We have reached the final substantive chapter and so inevitably the "bottom line" has to be placed before the reader! In a study of costs and benefits, it might appear relatively simple to compute the financial costs and benefits to the carers but, unfortunately, even this area is very far from clearcut.

Baldwin<sup>1</sup> has recently examined the economic costs of caring for a disabled child in terms of the extra costs incurred and income foregone. She begins her comparison between a sample of applicants to the Family Fund, which assists families with a disabled child, and a control group of families from the Family Expenditure Survey (FES) with an interesting outline of the problems involved in this exercise.

Most of the previous studies tended to focus on income rather than on expenditure. Studies on expenditure are always subjective. Previous studies dealt with adult disabled rather than children. Furthermore, calculations of income foregone "have all the weaknesses of hypothetical estimates based on imperfect knowledge".<sup>2</sup> And a final problem is that parents are sometimes reluctant to admit that their handicapped child is a financial burden or may wish to stress the child's normality rather than point up the differences. Add to these difficulties the long standing problems of

all studies on income and expenditure with regard to over estimation and under estimation of expenditure on certain commodities and a natural reluctance on the part of many respondents to reveal their true income, and one begins to wonder if economic costs are not as difficult to pin down as social costs.

However, Baldwin was not deterred by these difficulties from establishing that the care of a disabled child did involve considerable financial costs to the family. "For families in this study the financial impact of the child's condition was considerable and pervasive, affecting not only parents' earnings and expenditure on the disabled child but also expenditure on themselves and other children, the timing of financial decisions and the general management of money". No doubt remains after the evidence produced in this study that severe disablement in a child has a substantial impact both on the families income and expenditure.

The present study examined the question of extra costs, income foregone and attitudes to State benefits received by the carers. There was a significant difference between the two groups of carers on the question as to whether looking after the cared-for person made life more expensive for the carer. The figures are given in Table 9.1.

TABLE 9.1 : WHETHER LOOKING AFTER CARED-FOR PERSON  
MADE LIFE MORE EXPENSIVE FOR CARER

%	Carers of the Elderly	Carers of the Handicapped
YES	27.5	57.5
NO	72.5	42.5

( s = .0000 )

When asked to elaborate, the carers of the elderly mentioned possible wages foregone (6), extra heating costs (6), special food (5), transport (4), doctors' fees and medicines (3)

The carers of the handicapped listed extra costs for clothes and shoes (21 times), transport (10), medical expenses (7), extra heating (3), special foods required (3), income foregone by cared-for person (2), costs of laundry (1). The handicapped child was thought to be particularly "hard on shoes" and to require "special kinds of clothes". Baldwin's parents also stressed the extra clothing needs and higher clothing costs and similiarly with shoes.<sup>3</sup>

Carers of the handicapped reported:

*"The main extra cost is transport, taking him to the school bus and collecting him each day"*

*"He would be more help on the farm if he were normal"*

*"I had been paying doctors' fees until she was two years of age"*

"She requires a lot of shoes and stockings. She has to be taken to the bus and collected each week-end"

"If he wasn't handicapped he would be able to work and keep himself"

"I have to buy tablets and other medication"

"There are special clothes required for handicapped people. I feel that voluntary organizations seek a lot of financial assistance from me through raffles and other functions held to support the handicapped and their workshops and schools"

"Every trip we make to Cork is expensive and we have to go every two weeks. It is seventy five miles each way"

"Because of his illness, diabetes, it becomes quite expensive. Yet, we can just about keep him on his weekly allowance"

"Food - Michael has a very hearty appetite"

#### Carers of the elderly:

"I need special bed clothes and they do not last very long. There is also the cost of coal and fuel"

"As I live seven miles from her, it can be quite costly on petrol because I go to her house almost every day"

"Extra heating is needed when a person is confined to the house"

"He has a lot of food fads. He gets notions for different things that I wouldn't normally have"

*in the house. Then he uses a lot of milk and a lot of sugar"*

*"I have never weighed up the cost, although I suppose there is more heat used and the incontinence pads are expensive"*

*"I have to pay someone to get an evening meal for my husband and children which I am unable to do myself. My mother also likes a little drop of brandy and brandy is fierce expensive"*

*"Electricity and heating are very expensive and I have to keep a fire on in her room all through the summer"*

*"We have a gas fire on all day and, as you know, you cannot get much anymore for £20"*

*"She likes special foods which I get for her and there are also cosmetics which she likes to have and which I would not like to deprive her of"*

The two groups were similiarly concerned (62 and 60 per cent) that carers "like themselves" should receive more help from the State. When questioned on the State benefits, a good deal of uncertainty about these benefits and entitlement became evident as Briggs and Oliver<sup>4</sup> also discovered in their study. 37.8 per cent of carers of the elderly and 54.8 per cent of carers of the handicapped said they received State benefits. The difference is probably explained by the fact that the Prescribed Relatives Allowance is a means-tested benefit paid to elderly themselves as a supplement to their

pension of £24 per week, while the Domiciliary Care Allowance (£70 per month approximately) is not means-tested in relation to the parents' income. Only in cases where a disabled person has an income, e.g., interest from a compensation award is the benefit means-tested.

In the case of the carers of the elderly, thirteen were receiving the old age pension in their own right, being over 66, seven were in receipt of the Prescribed Relatives Allowance, three received the Widows' Pension and one the Deserted Wives Allowance. Three received Disability Benefit and one has a U.S. retirement pension.

What did come through was a fairly high degree of uncertainty (20 per cent and 25 per cent respectively) on the part of carers as to whether they were entitled to the Domiciliary Care Allowance and the Prescribed Relatives Allowance. They were unfamiliar with the official names of these benefits and unsure of where they came from. This did not make our task any easier.

Carers were uncertain too as to whether they were worse off or better off financially as a result of their caring role as shown in Table 9.2.

TABLE 9.2 :      WHETHER CARERS FELT THEY WERE BETTER OFF  
OR WORSE OFF FINANCIALLY AS A RESULT OF CARING

%	Carers of Elderly	Carers of Handicapped
Worse off	30.1	21.8
Better off	26.9	12.8
Not sure	43.0	65.4

( s = .0100 )

Obviously, only a much more detailed independent examination of income and expenditure figures on the lines of Baldwin's study could hope to gain an accurate picture. But attitudes to State benefits came through at the end of the interview when the carers were asked if they would like to add anything or mention anything they felt had been omitted. Among the 48 per cent of carers of the handicapped who gave suggestions, 21 per cent advocated extra financial help. Among the 35 per cent of the carers of the elderly who gave similiar suggestions, 28 per cent mentioned increased State benefits.

Carers of the handicapped:

*"I think that there should be more financial help from the State. £39 wouldn't take us very far"*

*"I think that I should be getting money when he comes home on the weekends and long holidays - money for clothes especially"*

*"The handicapped allowance should be increased as the child grows older and continues to be looked*

*after at home"*

*"I should be entitled to more financial help as her father is not working due to arthritis which he has for the past ten years"*

It must be said that money did not feature as high on the priorities of this group as it did among the carers of the elderly who expressed themselves in a much more forthright manner on this subject.

*"I think I should get some little payment from the Health Board or the Department of Health. A home help gets paid and she only spends so many hours a day with an old person. I am at it all the time. We are always hearing what it costs to keep an old person in a Home. I would be most grateful if you would do something for the likes of me."*

*"If somebody came to see the situation for themselves, to see if he could get an extra bit of money. It's wrong that a woman can go out to work and get paid as a home help to look after some old person. Whereas the person doing it for their own mother at home gets nothing and it's getting harder to manage financially all the time."*

*"There should be more information for the elderly about their entitlements. So many old people have nobody to look after them and there must be scope for home helps. If the new married women knew about it, they would be quite glad of a few extra pounds for a few hours per day."*

*"The money for caring is very poor indeed. I only get £36 per month from the Health Board and Mary*

*gives me £5 out of her pension. But if she were in a Home it would cost the State £200 a week to keep her."*

*"There would be more people looking after the elderly if the money were more realistic. I do what I do from love, but I cannot for the life of me understand why I am not entitled to the Prescribed Relatives Allowance. I was told I couldn't get it unless my husband was dead! My father-in-law needs constant care and it would only be right that I should get some little reward from the State because sometimes the going can be quite tough."*

On the other hand, it must be stressed that the majority of the recipients expressed satisfaction with the Domiciliary Care Allowance and the Prescribed Relatives Allowance.

*"It covers (the Domiciliary Care Allowance) the cost of the initial expenses for him. It is good enough"*

*"It is a help to buy things for her. It is good enough at present"*

*"She manages fine on it"*

*"I am satisfied with it anyway"*

*"At this stage of his life it doesn't cost a lot"*

*"It is a help. Bernard is very young yet. His needs are small"*

*"I think it is good enough"*

*"It is all right for me anyhow, but in different situations it may not be adequate, especially if somebody has to hire help"*

*"Keeping George doesn't cost a lot"*

*"It is good enough with the way the Country is to-day with the recession and so on"*

*"It is enough to keep us going. I can save a little on it"*

Now, in relation to the carers of the elderly:

*"What I am getting is adequate. I manage fine. We are very comfortable"*

*"I don't want any money to do what I am doing. It is a pastime"*

The main finding here is that there is need for more information on the entitlements of carers as a great degree of uncertainty prevails. There is a minority whose life is a struggle either because of already low income or because of special needs on the part of the cared-for. While dissatisfaction was expressed by a minority and while increased State benefits appeared among the suggestions of the carers, there was a greater desire for new or better social services for both elderly and handicapped - the perennial dilemma in this area between increased benefits or services in kind.

WORK OUTSIDE THE HOME

Only 4.7 per cent (4) of the carers of the handicapped worked outside the home as opposed to 21 per cent of the carers of the elderly. Bearing in mind that 26 per cent of the carers of the elderly are male, it will be appreciated that the participation of female carers in the workforce full-time or part-time is minimal at 8.6 per cent. Asked if they worked outside the home before they assumed the caring role, 27 per cent of the carers of the elderly said they did as opposed to only 8.4 per cent of the carers of the handicapped. This brings us into the hypothetical domain about which Baldwin expresses caution. These responses are summed up in Table 9.3.

TABLE 9.3 : ATTITUDES OF CARERS TO WORK OUTSIDE THE HOME

%	CARERS OF THE ELDERLY			CARERS OF THE HANDICAPPED		
	Yes	No	Not Sure	Yes	No	Not Sur
Whether carer regretted not working outside the home ( n = 168 )	14.1	88.9	-	16.5	83.5	-
Whether carer would be seeking work outside the home were it not for caring ( n = 165 )	13.5	82.0	3.8	20.3	75.9	3.8
Whether it is solely because of caring role that carer is not working outside the home ( n = 165 )	20.0	77.6	2.4	25.0	73.8	1.3
Whether carer felt that many sacrifice a job to look after an elderly parent or handicapped child ( n = 196 )	67.3	20.9	11.8	67.4	16.3	16.3

The lack of job opportunities as well as the other family responsibilities of most of the carers may explain the relatively low number of would be "takers" of jobs outside the home. The much larger proportion who believe that many people sacrifice a job to care for a relative may represent a lingering stereotype of the single girl who gave up her job to care for her ageing mother, but it may also reveal a conviction about lost opportunities on the part of many of the carers.

This set of attitudes in relation to working outside the home was investigated further by means of a problem which was posed for the carers. It was posed somewhat differently for men and women.

The women carers were asked:

"Supposing a good friend came to you with this problem. She has a job as a secretary in an office in town but now her mother has got a stroke and needs continual care for the foreseeable future. Should she give up her job and mind her mother or should she seek some other way out? How would you advise her in her dilemma?"

The men were asked:

"Suppose a good friend of yours came for advice. His mother has had a stroke and needs continual care for the foreseeable future. He works in a drapery shop. Should he give up his job and mind his mother or should he seek some other way out? How would you advise your friend in this dilemma?"

There were four general responses: one was to advise the friend to give up the job and look after the mother; the second to advise the friend very definitely to keep the job; the third was to advise the friend to seek some

other way out rather than giving up the job; the fourth group, the undecided, were unable to advise the friend.

It was most interesting to note the minute attention which carers gave to their answers. It was clear they had thought a lot about this question and they got down to very specific recommendations. They obviously found the question interesting and some of them gave long replies. They identified with the dilemma, to the point of advising as if the friend was actually present. The different responses are outlined in Table 9.4.

TABLE 9.4 : ADVICE TO FRIEND RE CHOICE BETWEEN CARING FOR MOTHER OR KEEPING JOB

%	Women to Women Friend (n=161)	Men to Men Friend (n=34)
Would advise friend to give up job and care for mother	47.7	41.1
Would advise friend to keep job	15.5	9.0
Would advise friend to take some other way out rather than give up job	19.3	44.0
Was undecided as to how to advise friend	14.3	5.9

There was an abundance of advice and only one person felt that she was "in no position to give any advice to anybody". What is quite interesting is that 47.7 per cent of the women and 41.1 per cent of the men felt that the care of a mother was more important than a job. The men tended to advise the friend to take some other way out rather than give up the job. Men were less likely to be

undecided and they were more definite in their advice. This advice to seek another way out was often a very well worked out alternative, involving the use of home helps, part-time instead of full-time work, the finding of paid or voluntary help even at the cost of paying as much to such a home help as the person earned themselves if necessary, since a job might not be easy to get in the event of the mother's death.

Women:

*"If she can afford to give up her job, she should. I feel she should mind her mother at any cost. I'd tell her to give up the job and mind her mother. She will only get the opportunity once and she will never regret it."*

*"Ideally she should look after her mother. That means giving up her job. However she should be financially helped by the State to compensate her for doing this."*

*"If there is nobody else to look after her mother, I think she should give up her job. The decision has to be hers and it's not an easy one."*

*"I would advise her to give up her job and look after her mother as she might not have her for long and if she neglected her she would regret it later."*

*"I would tell her that she should leave the job and look after her mother. She can get another job but she has only one mother."*

*"I think she should give up her job because her mother*

reared her and cared for her when she was young."

"I would advise her to give up her job and look after her mother. It will be rewarding at the end of the day for her and it may only be for a while."

"She should get a home help. How could she give up her job? I wouldn't advise her to give up her job. They are so scarce, especially while there are other forms of help, for example, a hospital. Of course, one can't throw one's mother out either. But jobs nowadays are so scarce that you have to grasp them and hold onto them."

"She should make very sure before giving up her job because jobs are scarce and she would be giving up her independence."

"She should hold onto her job. She has her own life to live. If she were to get somebody to help her to mind her mother, such as a home help, it would be far better than giving up her own job."

"Her first duty is to home. She should get leave of absence for about six weeks. If no improvement came in the mother's condition she should go to the social worker to discuss the whole question of her care. She shouldn't give up her work totally but if necessary should get part-time work, if that is the only option left. Perhaps, it would be possible for her to acquire the assistance of a home help and still maintain her job."

"I would be very slow in advising her to give up her job. She may not get employment at a future date when her task of caring for her mother is over. She should get a home help instead."

"I think she should give up her job to mind her mother or maybe it would be possible for her to work part-time and get someone in to care for her mother for those hours when she is at work. I would tell her to make up her own mind, but if it were financially possible for her to give up her job, that is one thing. If this were not possible to do then the rest of the family ought to contribute their share and this would help her to give up her job and cope at home. It is certainly a hard decision. From my own experience, I think that if she were to decide to give up her job she would find she would be very happy in looking after her mother."

"It would all depend on the person. Some people are just not "cut out" for looking after old and sick people. It is a very serious step to give up a secretary's job. I would not know how to advise unless I knew the person very well. If she's dependent on her job then I suppose she should try and get somebody in. I wouldn't like her to neglect her mother but it's very hard to give up a job as they are so hard to find at the present time. I feel that she should stay at home but I would be very slow to tell her that. I would tell her to make up her own mind but, if financially possible, I would give up my job."

"I think she should give up her job. Her mother should come first."

"It would depend on her age. If she were a young person then she should keep her job because she has her own life to live. If she were married, I think she should give up her job. If she were single, I think it would be very unfair to ask her to give up her job. She might perhaps

employ a home help or even consider residential care. Her mother cared for her when she was a baby. On the other hand, she can't afford to ruin her life looking after somebody for a long period of time. She has to make a life of her own."

"I would advise her to give up her job and mind her mother. I know a lot of women to-day would not take very kindly to this advice!"

These were the reactions of the women carers. Now for the advice given by men:

"If he could afford to give up his job, he should. Old people should be left in their own homes if at all possible. I would tell him to give up his job. His mother won't be always there. He will be rewarded for it."

"Give up his job and look after his mother. She won't be always there. Indeed he will miss her when she is gone."

"He should care for his mother and give up his job for a short time. The parents like their own to look after them. It would be most important that he would not allow his mother to be put into a Home. He ought to make every effort to arrange things to avoid this much at least."

"I feel he should not give up his job. But I suppose it would depend on whether he could afford to or not."

"I would tell him to keep his job and to get someone in to look after his mother."

"It depends on the nature of the person. The

mother should be placed in a Home. The son should then pay towards her keep there and call to see her regularly. If the mother dies after his giving up his job, then mother and job would be gone."

"Firstly, he should try to get some relative in to mind her. If that fails he should try to get her into a Home. If he were a married man he should take her into his own home. He could land himself in a mess financially if he gave up his job. Then he couldn't look after her anyway. That's only common sense. It would, of course, depend on whether he was single or married."

"It's hard to say. It's hard to give up a job. Jobs are scarce. Perhaps he could get someone in to look after her. It would depend on the kind of person he was. I would advise him to look after her at home if at all possible."

"People differ. Some men are different from others. Some seek help. I would say a home help to live in would be the solution here if that could be arranged."

"It all depends on the man. Some men just couldn't do it. In giving up a job I suppose a lot would depend on his age. It's hard to a young man to give up his job, when jobs are so scarce and he might want to get married. I think he'd be taking a very serious step if he gave up his job. I couldn't see my sons doing it. He should weigh up all the pros and cons. I think he would be better off getting someone in to look after his mother. Anyhow, men are not good at looking after old people."

### WOMEN VERSUS MEN AS CARERS

It has been alleged more than once in the literature of the 1980s that the care of the elderly and the handicapped in the family falls on the shoulders of women, most often housewives, who are prevented from following a career or going out to work because of the caring role. It has been suggested also that they get precious little help from their men folk. The reason for this, it is said, is because the care of the elderly and of children is culturally defined as women's work, so men are not expected to be able or willing to act as principal carers or even to help the women who bear the burden of caring.

The carers were asked whether they considered that men or women are better at caring. The carers of the elderly were asked about elderly cared-for and the carers of the handicapped about handicapped children. The possible answers to the question were that men were better carers, that women were better carers or that both were equally good at caring. The men did not receive a single vote, even from among their own ranks ! The opinions are set out in Table 9.5.

TABLE 9.5. : WHETHER WOMEN OR MEN ARE BETTER CARERS

%	Carers of Elderly	Carers of Handicapped	Women Carers	Men Carers
Men are better carers	0.0	0.0	0.0	0.0
Women are better carers	59.8	78.6	61.0	56.7
Both are equally good	40.2	21.4	39.0	43.5
	(s = 0.008)		(s = 0.846)	

The conviction that women are the better carers was supported as strongly by men as it was by women carers. It is agreed that women are generally superior but that sometimes men can be equally good. The reasons given were as follows:

- (i) men have proved to be competent carers, e.g., husbands who can look after their handicapped child or elderly cared-for person just as competently as the carer herself.  
(mentioned 47 times)
- (ii) Women know the art of caring better than men. They have more skills, domestic and nursing. They can cope better with the stresses and strains of caring. (37 times)
- (iii) Women are almost always more patient and understanding than men and these are the vital qualities. (25 times)
- (iv) Caring is, in fact, a woman's role. They are the ones who actually do most of the caring. (24 times)

Others went on further to say that caring is the woman's role by nature and by instinct. Here was evidence of a clear role division between men and women (18 times)

- (v) It depends on the individual not on the sex or gender. What matters is the "caring bent" which is not confined to either sex. Some people have the ability to care for others, some do not. (17 times)
- (vi) Men are poor at caring. It is "just not their line". As one carer put it, "men don't have what it takes to look after a normal child let alone a handicapped one". (10 times)

Despite the majority opinion that women are the better carers, there is good support for the notion that men could and sometimes do perform well. However, one detects here an overall cultural norm, accepted by both women and men, that caring is normally the proper task of the woman.

The carers were asked whether they felt that men could be doing more to help with the care of feeble elderly or handicapped children in the home and also whether the task "always falls on a woman with nobody else really doing very much to help". The responses are outlined in Table 9.6.

TABLE 9.6 : SHARING OF THE CARING TASK  
BETWEEN WOMEN AND MEN

(a)	<u>% CARERS OF ELDERLY</u>			<u>% CARERS OF HANDICAPPED</u>		
	Yes	No	Not Sure	Yes	No	Not Sure
Whether men should be doing more	65.2	19.6	15.2	61.2	18.8	24.0
	(s = 0.6138)					
Whether caring always falls on a woman	63.1	24.3	12.6	87.1	3.5	9.4
	(s = 0.0001)					
(b)	<u>% MEN CARERS</u>			<u>% WOMEN CARERS</u>		
	Yes	No	Not Sure	Yes	No	Not Sure
Whether men should be doing more	66.7	13.3	20.0	64.6	22.0	13.4
	(s = 0.4790)					
Whether caring always falls on a woman	51.7	24.1	24.3	67.1	24.4	8.5
	(s = 0.0848)					

Within an overall framework of agreement it is accepted by both sexes that men should be doing more in caring situations and that the female carers bear the burden of caring without much help from their menfolk or others. This shows substantial support for the thesis of writers such as Finch and Groves<sup>4</sup>, Briggs and Oliver<sup>5</sup> and many others. For example, Briggs and Oliver comment on the issue of support from other members of the family, "A

common story is of all the other members of the family unit fading away and leaving all the work and responsibility to one person. This leads to enormous bitterness and resentment."<sup>6</sup>

A significant finding is the degree to which the carers of the handicapped (87 per cent) feel that the caring task falls on them with nobody else doing very much to help. It seems to contradict earlier suggestions that other family members helped, especially the husbands. But it probably reflects a basic feeling on their part that the help and moral support they receive within the family are peripheral to the actual volume of caring, day in day out, which falls on the carers alone. Lewis and Meredith<sup>7</sup> were led to believe that "Kin and network of friends and neighbours can play a vital role, especially in sustaining the carer's morale, but their contribution to the performance of the caring tasks is strictly limited." But there is very little trace of the bitterness and resentment mentioned by Briggs and Oliver. The two or three wives who complain bitterly about their husbands do so, not because of their failure to help out, but because of their failure to run their farm or business well, thus bringing the family into poverty. ( See Life Histories, Case No. 82)

The absence of any great sense of outrage at the inequality

which is perceived reminds one of Runciman's<sup>8</sup> similiar findings in regard to social class and of Marx's "false consciousness" in those who failed to identify themselves with the class struggle. Ungerson also invoked "false consciousness" in the context of carers who were happy.

#### ATTITUDES TO RESIDENTIAL CARE

Residential care is never far from the minds of the carers. In the Diocese of Kerry full-time residential care in large institutions has been, until very recently, the only alternative to care in the community for the frail elderly and mentally handicapped children. In the case of the elderly, the "County Home" continues to carry a residue of workhouse stigma though this seems to have lessened over the years.

But entry to a residential setting is almost always a permanent move for an old person except in cases where it does not work out and the old person has a family willing to take them home again. The move to a residential setting is, therefore, an extremely serious step for both cared-for and carer alike. Both are generally reluctant to take it. It has an air of finality about it. Temporary residential care occurs only through hospitals when the elderly person is ill. There is no other short-term residential care available. So it is only when caring becomes too difficult for the

carer or, when the carer needs a break, that residential care is sought. (See Life Histories, Case No. 10, where short term hospital care was found.) But having said that, it can be very difficult to get a place in State-run Homes for the elderly with the result that private nursing homes are a growing industry. There are now two hundred and thirty six of them in the Republic of Ireland and thirty of these are in the Health Board Area of this study.<sup>9</sup>

In the case of the mentally handicapped, a choice was usually made as soon as the handicap was discovered. The choice was often an extremely emotional one, coming so soon after the initial trauma. The problem of schooling at a later stage could call for a new decision time. There were strong feelings on the part of many of the carers on this issue. Again, the choice has been between the family home and large residential settings, though in latter years, the residential home has been adapted to smaller family type houses. The St. John of God Brothers have two family type homes in Tralee at some distance from their training centre. But, as yet, no programme has been initiated in Kerry to allow moderately or severely handicapped adolescents to begin to leave their family home or the residential settings to lead independent lives. Schemes have been in existence in other parts of Ireland in recent times, under the auspices of the Brothers of Charity, where young adult handicapped are

set up in flats near training centres with as little supervision as possible.

Of course, 23 per cent of the cared-for in this study are in residential care at St. Mary of the Angels, Beaufort, on a five-day week basis and return home for weekends and school holidays. Their parents are accustomed to having their children away from home and, as will be seen later, these carers have a more positive attitude to residential care. However, they are aware that their children will have to leave the Homes at 18 years of age and so they have fears for the future as described earlier.

The importance of carers "letting go", of "making the break" with their handicapped children as with normal children has been powerfully argued by Richardson and Ritchie.<sup>10</sup> There is an understandable tendency, as the parents grow older, to regard the handicapped as a perpetual child, a helper and a consolation in their old age. This is unlikely to be in the child's/ adult's long term interests. It can arise because of parents' natural protectiveness of the weaker child, or because parents like to feel they are needed as they grow older. In this case, the absence of suitable models of accommodation for independent living for mentally handicapped adolescents and adults can act as a further disincentive to parents to "make the

break". "Despite the considerable interest in the forms of provision to be made for people with a mental handicap there has been surprisingly little research on the perspective of parents on the move from home ...."<sup>11</sup> A study of elderly parents by Alison Wertheimer<sup>12</sup> suggests that "the strong mutual bond of affection between parents and handicapped fosters an acceptance that the son or daughter will remain at home indefinitely". She concludes that an "abnormal" or atypical social pattern has become normal with these families seeing themselves not as one of a couple but as "a threesome". This view is confirmed by the results of a North Wales study by Grant et al. which found that parents show a great sense of affection for their sons and daughters and little trace of resentment at their current situation. With respect to the future there was a number "who found this subject difficult to talk about ... almost taboo. For these people life seemed to be lived on a day to day basis in the vague hope that something magical might turn up".<sup>13</sup> Another study, however, finding parents to prefer to keep their son or daughter at home concluded, in contrast, that this arises because of "both the unacceptability of the options of which they are aware and their lack of knowledge of possible alternatives."<sup>14</sup> There is a good deal of evidence in the present study to support both of these conclusions.

The carers in this study were questioned at different points in the interview on their attitude to placing the cared-for person in such a setting. Early in the interview the question of a crisis involving a choice between home and the possibility of residential care was posed. Such a decision had been experienced by 46.8 per cent of carers of the handicapped and by 13.5 per cent of carers of the elderly. The decision to keep the cared-for person at home was the option chosen by the majority in each group. Only 23 per cent approximately of the carers of the handicapped did, in fact, send their child to a residential home. The sample of elderly could not include people in residential care by the nature of the study and from the nature of provision as there is no temporary care available. The handicapped could include residential care attending school and returning home at weekends and for holiday periods.

The thought of residential care is one which is obviously on carer's minds, but while they have nothing in particular against such institutions, they see them as a last resort in their own case. When asked an open question as to what they thought of residential homes for elderly and handicapped children, the majority of the comments were classified as "favourable". But there were some negative comments also as shown in Table 9.7.

TABLE 9.7 : WHAT CARERS THOUGHT OF RESIDENTIAL CARE FOR ELDERLY AND HANDICAPPED CHILDREN

Comments %	Carers of Elderly	Carers of Handicapped
Very positive	24.0	36.4
Positive	59.0	46.8
Negative	12.0	15.6
Very negative	5.0	1.3 (n=179)

(s = 0.1300)

There was no significant difference on this question between those whose children were at home all the time and those with children in residential care for five days each week.

In marked contrast was the carers' responses to the next question as to how they would feel if they were forced to place their cared-for person in residential care. The replies are given in Table 9.8.

TABLE 9.8 : HOW THE CARERS WOULD FEEL IF THEY WERE FORCED TO PLACE CARED-FOR PERSONS IN RESIDENTIAL CARE

%	Carers of Elderly	Carers of Handicapped
Lost	30.8	44.6
Very disappointed	38.5	47.0
Somewhat disappointed	11.5	4.8
Relieved	7.7	2.4
Guilty	11.5	1.2 (n=187)

(s = 0.0045)

The great majority of carers obviously see residential care as the last thing they would choose. To see the

cared-for person confined permanently to an institution signals break down and failure of their caring role. At least part of the reason for this reaction can be explained by how the carers felt the cared-for would react to being placed in a residential home.

Table 9.9 shows the responses:

TABLE 9.9 :    HOW CARERS BELIEVED THE CARED-FOR PERSON  
WOULD REACT TO BEING PLACED IN RESIDENTIAL CARE

Cared-for person	Carers of Elderly %	Carers of Handicapped %
Would fear it	23.9	14.8
Would resent it	45.0	44.4
Would feel hurt	13.8	18.5
Would not mind	10.1	13.6
Would like it	0.9	1.2
Don't know	6.4	7.4 (n=190)

There was an interesting comparison on this question between the carers who had their children in residential care and those whose children were at home all the time. While there was a significant difference in attitude between the two groups there was still a good deal of negative attitudes attributed to the child as shown in Table 9.10.

TABLE 9.10 : HOW CARERS BELIEVED THE CARED-FOR PERSON WOULD REACT TO BEING PLACED IN A RESIDENTIAL HOME

Cared-for person	Carers with child in residential care	Carer whose child lives at home all the time
	%	%
Would fear it	6.7	16.9
Would resent it	13.3	52.3
Would feel hurt	26.7	16.9
Would not mind	40.0	7.7
Would like it	6.7	-
Don't know	6.7	6.2
	(n = 15)	(n = 65)

(s = 0.0018)

Only one carer said the child would like the institution. It seems that the carers and the cared-for persons are keen to avoid "relegation" to the "lower division" of residential care as they know it.

When asked what they supposed might force them to seek residential care for their cared-for person, the carers said that only a total collapse of their own health and a failure to find another family member to take on the task would force them to seek residential care. If the cared-for person's health or behaviour were to make caring impossible at home this, again, would force the carer to seek residential care. But when they were pressed to say whether they thought that a time would come when they would no longer be able to look after the cared-for person and so would have to seek a place in a residential home, the uncertainty about the future came through as will be seen from

Table 9.11.

TABLE 9.11 : WHETHER CARERS THOUGHT THAT A TIME WOULD COME WHEN THEY WOULD NO LONGER BE ABLE TO LOOK AFTER CARED-FOR PERSON AND WOULD HAVE TO SEEK A PLACE IN A RESIDENTIAL HOME

(n = 187) %	CARERS OF ELDERLY			CARERS OF HANDICAPPED		
	Yes	No	Not Sure	Yes	No	Not Sure
Whether carers thought a time would come ... when they would have to seek a place for cared-for person	27.6	47.6	24.8	26.8	41.5	31.7

The high degree of those who were "not sure" included a number who simply not bring themselves to face the possibility. Those with children in residential care had as many fears for the future as the others since they expected that they would have to come out when 18 years of age and find a place in a Workshop or Training Centre if possible.

However, the suggestion of short-term residential care for 2 or 3 weeks to give the carers a break met with a much more positive reaction as will be seen from Table 9.12.

TABLE 9.12 : HOW CARERS FEEL ABOUT SHORT-TERM RESIDENTIAL CARE

%	CARERS OF ELDERLY			CARERS OF HANDICAPPED		
	Yes	No	Not Sure	Yes	No	Not Sure
Carers see it as a good idea	56.6	30.1	13.3	69.5	15.9	14.6

The majority thought this would be a good idea even though they also felt that the cared-for would either resent it or refuse to go. In this contest, the existence of such a facility in their area and an opportunity to see, if not experience it would show its usefulness for both carer and cared-for. No such short-term care exists apart from one or two holiday schemes run by voluntary organizations. Such short-term care might be the bridge which could provide the carer and the cared-for person with the opportunity to see the future and find out that it works, to echo Beatrice Webb on her return from Russia. It would be extremely important that they should have done so before an emergency such as the death of the carer brings the handicapped person to the attention of the social services for the first time as Richardson and Ritchie point out in their conclusion.

These authors have given a new stimulus to thinking through a policy which promises to remove most of the anxiety of parents of the handicapped about the future. It involves initiatives in housing where the mentally handicapped adolescent or adult can be gradually taught to live as independently as possible. It also involves counselling of parents in the painful process of "letting go". But it does become easier if the parents and cared-for have the opportunity to try it out for short periods before the need for it becomes

compelling.

The lack of temporary residential care for the elderly means that carers find difficulty in having a break or taking a holiday. In the past year with the cutbacks in the hospital service, the possibility of placing the elderly person in a hospital for a week or ten days no longer exists. Despite the recommendation of the 1968 Inter-Departmental Committee that temporary residential care be provided nothing was done in this area. The 1988 Report on Services for the Elderly recommends Community Hospitals providing

- (a) assessment and rehabilitation of elderly patients
- (b) convalescent care
- (c) respite care to support caring relatives
- (d) nursing care for terminally ill who can no longer be cared for at home
- (e) information, advice and support for those caring for elderly in the home.<sup>15</sup>

One hopes that this recommendation is acted on. Carers would welcome it as indeed they would the new found concern for the caring relatives.

NOTES

1. Baldwin, S., 1985, *"The Costs of Caring"*, Routledge and Kegan Paul, London
2. Baldwin, S., 1985, op.cit., p.57
3. Baldwin, S., 1985, op.cit., p.165
4. Finch, J., and Groves, D., 1980, "Community Care and the Family: a case for equal opportunity", *Journal of Social Policy*, Vol.9 No.4, pp.487-514
5. Briggs, A., and Oliver, J., 1985, *"Caring: Experiences of Looking after Disabled Relatives"*, Routledge and Kegan Paul, London
6. Briggs, A., and Oliver, J., 1985, op.cit., p.114
7. Lewis, J., and Meredith, B., 1988, *"Daughters Who Care"*, Routledge, London, p.155
8. Runciman, W.G., 1966, *"Relative Deprivation and Social Justice"*, Routledge and Kegan Paul, London  
 Runciman studied samples from the different social classes and, applying John Rawl's theory of justice, concluded that the sense of inequality did not exist to the extent that the real inequality would have warranted. But the fact that people did not feel relatively deprived did not mean that social justice was being done them. "It might be objected that there are many manual workers who do not feel any relative deprivation on this account and who have no less self respect or pride in their work than workers in occupations which are more highly regarded by society at large. Are they to be convicted of false consciousness because they are not disposed to resentment or envy? But it will be clear from the sense which the contractual model gives to the notion of false consciousness that it does not require any individual to be roused to feelings of envy. It only means that if a manual worker, however contented, were to feel that manual workers are awarded too little status by comparison with non-manual, this feeling

of relative deprivation would be legitimate." (p.330)

9. Report of Working Party on Services for the Elderly, 1988, *"The Years Ahead"*, Government Publications Office, Dublin, p. 213
10. Richardson, A., and Ritchie, J., 1986, *"Making the Break"*, King Edward's Hospital Fund, London
11. Richardson, A., and Ritchie, J., 1986, *op.cit.*, p.18
12. Wertheimer, A., 1981, *"Living for the Present: Older Parents with a Mentally Handicapped Person living at Home"*, Campaign for People with Mental Handicap, p.2
13. Grant, G., Black, J., Wenger, G.C., and Humphreys, S., 1984, *"Progress Summary : Care Networks Project"*, Bangor, Department of Social Theory and Institutions, University College of North Wales
14. Richardson, A., and Ritchie, J., 1986, *op.cit.*,
15. Report of Working Party on Services for the Elderly, 1988, *op.cit.*, p.8

## CHAPTER 10

### CONCLUSIONS

#### SECTION 1

The study was a comparative one at four different levels. First, the carers of the frail elderly were compared with those of the mentally handicapped. Secondly, the findings in their Irish setting were compared with those of similar studies in Britain. Thirdly, the female carers were compared with their male counterparts. Finally, the concept of Community Care was in the dock throughout, as evidence came to light for and against the charges that it was really family care or care by women. Keeping these different dimensions before the reader made me feel somewhat like a juggler. I hope that the presentation did not prove to be too distracting. I shall now summarise what the comparisons have yielded towards our better understanding of the dynamics of caring. In a second section I shall make some policy recommendations for better allround support for carers in Ireland.

By not limiting the study to carers of the elderly I followed my own two main areas of interest but I also avoided the danger mentioned by Glendenning<sup>1</sup> of neglecting smaller groups such as the disabled at a time of new-found concern for the elderly and their

carers. The carers of the elderly are under the spotlight at the present time but one must recall Titmuss and the early euphoria about Community Care and stress that so far very little indeed has been done in practice for the carers by statutory social services. But it is nevertheless important to bring carers of all groups forward together. An important reason for this suggestion is the fact that the two groups had more things in common than they had differences. They tended to be women, to be housewives who did not work outside the home. The two groups did not differ significantly in regard to age or social class. There were significant differences in regard to marital status, the carers of the handicapped being for the very most part married and more likely to have other dependents. The costs, in both cases, were very similar and often severe. The feeling of being tied down, the lack of regular breaks and a sense of isolation and loneliness were felt equally by both sets of carers. Depending on the age of the mentally handicapped cared-for person, there could be hope for improvement as with normal children so there was an incentive to make their child more independent. Increased independence brought satisfaction to these carers whereas for carers of the elderly, the prospect generally was one of gradual decline. On the other hand, the real distinguishing feature in this comparison is the uncertainty and

fear for the future experienced by the carers of the handicapped. This is a very serious problem for carers who wonder what will happen when they become incapacitated or die. The carers of the elderly do not have this particular difficulty to contend with, although a small minority were troubled about how they would cope when the cared-for person died. (See Life Histories, Case Nos. 1, 25, 46)

The proportion of women among the carers of the elderly is high compared with British figures such as those in the Equal Opportunities Commission 1984. In this latter the proportion of women was 59 per cent while in this study 78 per cent of carers of the elderly were women as were 97 per cent of the carers of the handicapped. It would seem that where the cared-for person needs a large degree of help, the carer is the person who does the "daily grind" of personal care and supervision. It would not be true to say, however, that the female carers receive no help or support. The spouses are their main helpers who occasionally substitute for them when they are away or ill. But the more usual help from spouses takes the form of minding and of outdoor activities with the cared-for person. They give moral support also which, even in the absence of more tangible assistance, is still vital to the carers. This important form of support is sometimes underestimated in the literature.

Appreciation from a spouse, in particular, can affirm and reaffirm the carer in the trauma of handicapped birth and in difficult caring situations. Naturally it would be an even better support for the carers if spouses' help had a physical as well as a moral component in all cases.

The division of labour within the family, as evidenced in the study, would situate many of these families within the "neo-traditional family" in Goldthorpe's classification. The husbands' help went beyond that of the strict sex division of labour of his "traditional family" but fell far short of the state of affairs within his "thoroughgoing egalitarian family", where both parties are equally likely to be employed and "all family responsibilities are shared as agreed between the spouses on the basis of ability and preference and not on the basis of sex." The spouses in this study are the breadwinners, the wives, for the most part, stay at home and look after all dependents. The husband "helps". Hannan<sup>3</sup> studied this very question in the same part of Ireland and he confirmed that in one third of farm families, husbands helped with housekeeping and child rearing. His term was "modern" family as opposed to "traditional" family. This development was attributed by Hannan to education, the influence of the media, but, above all, to the values of the wife. This conclusion would seem to indicate that female carers can bring about

change in their spouses. Jilly Cooper's<sup>4</sup> optimistic prognosis is therefore pertinent to the future of caring. "The male is a domesticated animal which, if treated with firmness and kindness, can be trained to do most things".

Other family members also helped the carers to a lesser degree than the spouses and relatives outside the home less again. Neighbours gave a low degree of physical help to carers but, where they did, it was greatly appreciated. Carers generally did not expect their neighbours to do more than they were doing. In the case of the handicapped, neighbours were reported to give very little help. In the case of the elderly, who had no family or close relatives in the area, neighbours acted as carers. Sometimes, these carer-neighbours became home helps to the cared-for and this could be an important pointer to the future of Community Care both for the elderly who have no family/relatives in the area and for those with carers. They came very close to the paid volunteers of British Neighbourhood Schemes.

What does appear from the findings is that the care of the elderly and handicapped is primarily the domain of the family. Neighbours' help is largely confined to visiting, to providing companionship and pleasurable conversation. Where carers and cared-for are together on their own a lot this can be valuable. Hannan<sup>5</sup>

again found that among small farmers this form of friendly exchange was now the main contribution of neighbours in contrast to former times when neighbours worked together in groups, known as the "meitheal", and exchanged horses and machinery. Carers of the handicapped tended to find their companionship more within voluntary groups, especially associations such as the Down's Syndrome Association and the Parents and Friends of the Mentally Handicapped. They were less able than carers of the elderly to name friends of their cared-for persons. But it was important for them that anybody who helped them should do it because they liked the handicapped in their own right.

Community Care then does boil down largely to care within the family but there is a not inconsiderable contribution from relatives outside the home, from friends and from neighbours. But the perception of the community is that caring for dependents is the function of the family so that neighbours are not expected to step in while the family is present. Where there is no family to care, or where family care collapses<sup>6</sup>, neighbours feel some duty to assist provided they are not trapped day in day out. Wenger<sup>7</sup> sees the assurance that this will not happen as the key to the success of the Gofol project.

Social policy endorses and reflects this division of

caring where the family is expected to look after its dependents and, as Moroney says, the State tends to substitute for the family rather than support it. Very little help is offered. No home help were given to any of the carers in this study. The public health nurse is the mainstay of the elderly here, coming to visit those in need of nursing care and giving, in some cases, moral support to the carers. The social worker helps a minority of the carers of the handicapped. The role of voluntary bodies is slight, also - they tend to concentrate solely on the elderly who live alone. The recent Report on Services for the Elderly, 1988, has, for the first time, focussed attention on the special needs of the carers. The formation of the first Association of Carers in Dublin together with the Study of Carers, soon to be published, all highlight the need for increased support for carers, provided of course, that "Support for Carers" does not become "the everlasting cottage-garden trailer" of the nineties.

So, on the evidence of this study, it is true to say that care by the community and care in the community is largely care within the family. That said, however, we must not exaggerate; so due weight must be given to help and support from outside. Nor is it true to say that the care in the home is all left to women without significant help from anybody. This claim, too, involves exaggeration. What is indisputable,

however, is that women bear the main brunt of caring for both elderly and handicapped and in a larger proportion of cases in Ireland than in England.

When comparing the two countries, it has to be borne in mind that the findings of the present study might not be sufficiently representative to be generalised to another country, or even to an urban setting such as Dublin. The overwhelming majority were Catholic and devoutly so and this may have a strong bearing on the results. They are possibly less materialistic because of this. Abrams<sup>8</sup> was puzzled by the results of his later studies on neighboring that working class Catholics were more involved in caring than their counterparts. For Abrams as for Hadley and Webb<sup>9</sup>, religion was one of the factors which made for active involvement in caring or volunteer work with the frail elderly. Abrams did not see religion as directly causing this but rather as "mediating" it in some, as yet, unexplained manner.

Another reason for not generalising from this study may be that the families here are much more traditional than their counterparts in Britain. At first sight, this would seem to be very much the case. They would almost all fit in to Goldthorpe's 'traditional' model by virtue of the fact that the great majority of the married women do not go out to work but look after the children and elderly dependents. However, the rigid

sex division of work in the home which is the second criterion for Goldthorpe's classification is not borne out nearly as fully in the study. Many spouses help. Many of them regularly substitute as carers doing the personal care tasks. And some wives said that their husbands were as good at caregiving as they were themselves. These findings would tend to move up a substantial number of families into the 'neo-traditional' model of Goldthorpe or to the 'modern family' model of Hannan, as I stated earlier. Married women's low participation in the workforce, 20 percent in Ireland as compared with 60 per cent in Britain, is due to lack of opportunity rather than to traditional values at this point.

There is reasonable hope that husbands will share increasingly in the caring task in the future. Hannan, as we saw earlier, found that education, the media and, above all, the wife's values can influence progress in this direction. The current interest of social scientists stimulated largely by feminists, will give a strong impetus to this movement. Carers' Associations could provide information, and promote friendly rivalry between husbands as carers thus changing attitudes towards caring as "naturally" women's work. But the main agent for change must be the carer herself. She it is who must train her spouse and sons "with kindness and firmness to do most things". The media, the churches and the schools can help.

The costs to the carers are undisputed but they continue despite these heavy costs. Not only that, but the interviewers predicted at the end that the vast majority were likely to be able and willing to continue with the task. (See case histories 3,76.)

The reasons why carers continue are complex. They include feelings of duty and obligation, some direct rewards which offset costs and simply an emotional commitment to caring which goes beyond duty and reward. Many express this in terms of affection and love for the cared-for person and it can lead to high levels of self-sacrifice as seen from some of the Life Histories. (See Life Histories, Case Nos. 9, 81)

As well as the influence of feminist ideology mentioned earlier, there may be another factor at work which might serve to explain why rewards reported by carers are played down in the literature. This could be the consciousness of researchers that any good news about carers or about the resilience of families in the care of dependents would be seized upon by the present Government and used as an excuse for policies which give such inadequate resources to Community Care and to carers. The researchers, for their part, have no wish to provide ammunition for the Right. On the contrary. They seek to improve care in the community and, in particular, they wish to improve the lot of carers, women carers. This could, possibly, explain to some extent, why

researchers tend to be reward shy. Consequently, the costs are stressed while the rewards are not pointed up. These are two of the factors which may help to explain the gap in the British literature - the influence of feminist ideology and the fear of the exploitation of rewards by Government. I mentioned earlier the fact that, in many cases, the carers in the studies had already presented themselves to the social services or to organised groups, which could well indicate that they were in difficulties. In this study, the carers were drawn from the "general public" of carers. An analogy might help - to survey how people felt about their present state of health, one could interview a random sample of people going about their daily tasks at home or one could choose a sample in doctors' waiting rooms.

Abrams it was who called for a language of costs and rewards and he stressed that we needed to know a great deal more about the rewards to carers. He proposed that a language be invented which could translate the psychological costs and benefits into cash terms. The problem is that many, if not most, of the carers do not think in these terms, they are not consciously weighing costs versus rewards. Some, incidentally, do not even think of themselves as carers. "I'm a daughter, not a carer"<sup>12</sup>, was how one woman expressed it. To make social policy depend on this kind of

language would be to narrow it and the carers down to a greater reliance on materialistic considerations than seems necessary or appropriate. This calculative approach carries all the dangers of reducing the caring experience to cost benefit analysis derived from economics. This is not to deny the need in social policy to present issues in a materialistic and tight framework. But if you only use the language of cost-benefit in its economic sense you run the risk of losing a lot of the understanding of the question.

Like it or not, as a Catholic Archbishop aware of the need to avoid sliding into sentimentality or overly religious view of social life, I can only explain a large part of the dynamics of caring by concluding that the family remains a moral enterprise. The family fosters a set of values in which self-sacrifice can become something other than mere duty for a large proportion of people. The family does this quite naturally still. So the phenomenon of caring, in which social policy has such an interest, has to be explained without devaluing it simply to improve its case by emphasising only costs and disadvantages faced by carers.

Of course, injustices borne by women carers, highlighted in the feminist literature, are ongoing and enduring because the family remains a moral enterprise. That

is why the trap springs so successfully on women. But it does not help if, in order to attract support for women carers, one undermines or ignores the willingness with which so many women seem to enter caring relationships. Ireland may be atypical in this respect so that further study may be needed before generalising the results of the present study.

One has, then, the economic approach, advocated by Abrams, on the one hand and the self-sacrifice approach of Vanier on the other. The family has something of both. It is under pressure to be both. *"I do what I do out of love but I can't understand why I am not entitled to the Prescribed Relatives Allowance. I was told I could not get it unless my husband was dead! My father-in-law needs constant care so it would be nice to get a little reward from the State as the going can be very hard."* This carer illustrates the case well. There is pressure on the women to be calculative and not to be.

The solution would seem to be to seek justice for carers while continuing to depend on informal care. This can only be done by creating a supportive framework for the carer. Such an approach would be in the social policy tradition of Titmuss. One can argue that for the State to behave morally it ought to underpin the family as a moral enterprise and as a source of informal care

with greatly increased financial and support services. Social policies should support the family with benefits and services as opposed to the right wing policies which impose duties on it. You cannot get moral behaviour from families through this approach. Rather, the way forward is to enter a moral contract with the family. So if one opts for community and family care and argues for a framework of State support for the family as crucial it is because it is cost effective as evidenced by the Kent Community Care Project and other similiar projects. Family care frequently prevents and delays the residential alternative and could relieve it in certain cases. The State, for its part, should give the kind of support which ensures that the carer does not collapse. There is saving here too. Moroney<sup>13</sup> strongly advocated such a partnership between State and family. "There is no doubt the State is benefitting. The amount of social care provided by families far exceeds that of the State. It is impossible, furthermore, to assign a monetary value to it and it is inconceivable to speculate the cost involved if the State were to become the primary caring institution ... The State is fortunate to have families who care. The corollary to this is that families should also be supported by a caring society."

The clear tradition of Titmuss would lead us further to demand that the State create a moral context within

which it should foster the bonds of family and community. You have costs language which is necessary and valid but it is only half the story. You need another language, we might call it the "language of theory" to understand the benefits, rewards and self-sacrifice which need to be acknowledged rather than neglected or played down, as they have been in the feminist literature. Finally, I mention once again the fact that many carers reported that caring had enriched them as persons, had united their families and had made them less materialistic in outlook. In other words, the cared-for persons were drawing forth from their carers resources which they would never have discovered had they not been called forth in the caring relationship. This finding confirmed what Vanier and Craig have described. This must be qualified slightly by the fact that a minority felt that caring had damaged them personally and had upset their families. (See Life Histories, Case Nos. 28, 32, 36)

SECTION 11

In this final section I shall make recommendations for social policy in Ireland. The two aims of policy should be: (a) to reduce the costs to carers,

(b) to facilitate and strengthen the rewards.

To achieve these aims would be to make caring more stable with consequent benefits to carers, cared-for and the State. I shall first take the carers of the elderly.

A first step would be to include a parallel register of carers to that of the elderly at risk in the community. This could best be assembled at district level by a district liaison public health nurse as proposed in the Report on Services for the Elderly 1988.<sup>14</sup> At the local level the public health nurse could identify the frail elderly and their carers. Local knowledge and house to house visitation would be the way to find this information. Carers, whose age, health or other family responsibilities would indicate the danger of overwork or stress, should be kept "under observation" by the public health nurse. Appropriate help and support should be at hand if problems present themselves to carer or cared-for.

It seems imperative, also, to advocate an increase in the ratio of public health nurses to population. The Report on the Workload of Public Health Nurses, 1975,<sup>15</sup> recommended a ratio of 1: 2,616. The present ratio

of 1 : 3065 is considerably below target. The British figure is 1 : 1722. The Irish figure hides significant differences between health board regions. Since the public health nurse is the first line of defence of the elderly in the community and the main referral agent as well, it is crucial to the whole policy of Community Care that the service be greatly strengthened as quickly as possible. The alternative to increased numbers might be to involve SRNs in curative nursing or to train nursing assistants or to make clerical assistance available to the public health nurses. The Working Party on Services for the Elderly assumed, without question, that care in the community costs less than residential care. Their only doubt: "when is it more cost effective to care for the elderly at home and when is it more cost effective to care for an elderly person in a long stay hospital or nursing home?"<sup>16</sup> They commissioned research on this issue, two pilot schemes, one rural, one urban, to compare costs. It is only when elderly people in remote areas need continuous nursing care, which neighbours or family are unable to provide, that the planners, who were very well represented on the Working Party, began to take out their calculators ! Care in the community is going to cost a great deal of money and for too long adequate resources, in staff and finance, have not been directed to it sufficiently.

The training of the public health nurse should include

modules on carers and on how to support and affirm them. Specialised knowledge of the problem of incontinence would be important also. The ability to anticipate and to be ready for the next stage of caring when it comes, whether gradually or suddenly, will be one of the main skills to be imparted to trainee nurses.

Access to community social workers will also be necessary in cases of severe emotional stress to carers. Public health nurses cannot be expected to be counsellors as well as everything else, and the services of a community social worker, similar to that available in Northern Ireland, is needed. Social work departments will need to welcome carers among their client groups from now on.

A department of geriatric medicine in all general hospitals could be invaluable for assessment purposes and to raise the status of care for the elderly. The health board area of this study has two general hospitals only one of which has the services of a geriatrician. Distance and travel costs make access very difficult for many potential users of the service. Geriatric departments tend to encourage close liaison between domiciliary, community and extended care facilities and could be a powerful ally of carers of the elderly. They could promote a larger social dimension to the role of the G.P. also. The home help service also needs to be greatly extended and, in particular, the service must be made available

to carers in trouble. The problems can result from the illness of the cared-for person or of the carer. Women carers are as much entitled to a home help service as men carers even though the domestication of the male still has a long way to go. (See Life Histories, Case No. 13). The service should be expanded to include night sitting and weekend relief where necessary. There is a pool of potential home helps in the married women in an area where employment, even part-time, is so scarce. And there are all the unemployed men, the overall figure on the register running at 240,000 or thereabouts. We saw that some carers resented the fact that home helps were paid for doing what they were expected to do for nothing! The hourly rate for the home help is £1.50 in the health board area of this study and the vast majority work part-time. The solution here is a proper allowance for carers. There will, admittedly, be a delicate balance to be kept in expanding the home help service, giving carers greater financial recognition and keeping the unpaid services of neighbours in place. Further study in this area would be very interesting particularly as comparative to the Kent Community Care Project and the many others which have replicated it in Britain.

Day Care Centres are another welcome development and they are growing in number and appearing in small towns and villages. They give an important break to carers

and cared-for. Transport is a problem and financial help, from Government to voluntary bodies, to provide it will be essential if the elderly are to get to and from the centres.

Respite care for the elderly is a growing need as many district hospitals closed over the past eighteen months and most long stay hospitals, have up to now, had very little turn-over. The benefits of respite care accrue to the carer as well as to the cared-for. Consequently, the recommendations of the Report on Services for the Elderly, 1988,<sup>17</sup> that community hospitals be set up to meet this and a number of other needs should be acted upon. The proposal is that existing buildings should be adapted, where possible, and purpose-built facilities provided elsewhere. This idea would give residential care the flexibility it needs so badly. As well as "respite care to support relatives", there would be assessment facilities and rehabilitation facilities, convalescent care, day hospital and/or day care centre, and information advice and support for carers. This latter need for information and advice for carers should be a priority for health boards and should be provided in the community as distinct from the community hospital. This could be done through Associations of Carers or through other mutual help associations.

The only financial reward to carers is the Prescribed

Relatives Allowance, a relatively small supplement of £27.20 per week to the elderly person's weekly pension. Carers should be paid an allowance in their own right at a level related to income foregone through not being in outside employment, or, alternatively, to that of a full-time home help in an adequately paid home help service. As things are, the carers can identify with Othello's Last Speech, "I have done the State some service and they know it" They have a very strange way of acknowledging their debt ! As well as an income, the carers' social insurance (P.R.S.I.) should be covered fully so that the carer will have a parity with people who work outside the home in this important area.

One of the most important sources of support in the future must be mutual help groups such as Associations of Carers. The first association for carers of the elderly was set up in Dublin very recently. These self-help or mutual aid groups have great potential since they can make caring by the community more stable. Carers can share their experiences, knowledge and skills They will recall their worst moments but they will also share the good ones. The State should give at least minimal financial support to such groups by providing access to buildings, telephones and transport. Such policies need not cost a great deal of money but they could be of major help to carers who would be affirmed and strengthened in their caring role through

participating in their own associations.

Carers of the handicapped, to which I now come, have already found good support in their associations, such as the Down's Syndrome Association, the Parents and Friends of the Mentally Handicapped and the Faith and Light (Vanier) groups. State support here, as in the case of the carers of the elderly, would be equally valuable.

The traumatic time, at or after the birth of the handicapped child, should be eased in every way possible. Sensitivity is of the essence on the part of doctors and nurses. Mothers who have gone through the experience themselves could be called in to help. In this study, we heard of a group of mothers who volunteered to assist in this way but were not given any encouragement from the hospital or medical personnel. The "authority of relevance" still comes a poor third to that of knowledge and power!

Assessment should be ongoing and carers should be kept informed of their child's potential as well of its handicap. Since parents are prepared to work so hard for improvements, they should be encouraged to do so, but with kind words of caution also lest they suffer further disappointment later.

Carers of a handicapped child receive an allowance of £70 per month. This would scarcely pay for a normal child. The Economic and Social Research Institute <sup>17</sup> estimate a child under five costs parents an average of £19.60 per week while the figure is £28.30 per week for the 5 - 14 year old. It would appear that the present rate to the handicapped child needs to be considerably increased to meet the extra costs of the handicapped over the normal child.

The fears which carers have for the future of their cared-for persons should be faced. (See Life Histories, Case No. 68). Putting it off only makes matters worse. Carers should have access to social work counselling which would help them to come to terms with their fears. Social workers could assist in making concrete plans for the care of the mentally handicapped person when the carer is no longer available. These plans could involve transfer to a family member, or to a residential setting. In cases where no relative can be found to take on the task, and sometimes parents are very reluctant to impose it on their other children, counselling will be of little use without some definite housing options. Barbara Wooton would turn in her grave at the thought of social workers who had nothing more to offer carers in this situation than a sympathetic ear and warm words of cold comfort ! Sheltered housing has begun to grow up in the vicinity of training centres for the handicapped. Some voluntary organizations and

religious orders have set up such residential care where the handicapped are encouraged to live as independently as possible. Only such supervision and help as is deemed absolutely necessary is provided. The training centres include personal care, cooking, laundry and so on in the courses and training provided. Then there are also the L'Arche communities of Jean Vanier, which could be further developed in other areas - there are four or five already. The time to arrange the future is well before a crisis in the carer's health forces an emergency solution. The handicapped person should be given regular experience of the new surroundings, so that carer and cared for can become accustomed to living apart even for short periods. But if there is to be a future which can be contemplated without fear by the carers, a great deal of buildings will have to be provided for the handicapped throughout Ireland.

The lack of employment for everybody makes employment for mentally handicapped more difficult than ever. They can take part in training schemes with other young people but it is very difficult for them to find a job. (See Life Histories, Case No. 77) This will remain a chronic problem until employment prospects improve for the country as a whole. Sheltered employment must, therefore, remain the norm. But with some imagination, this can and is working

profitably in both senses of the word, and some very beautiful artifacts are being produced by the training centres. The St. John of God Workshop in Tralee provides employment for normal trainees as part of a Government youth employment scheme. They run a restaurant to which workers from the surrounding factories come for lunch and it runs at a profit. The mentally handicapped recently presented me with a Christmas Crib with porcelain figurines, made at the Centre. I never thought, when I watched them grow up at Beaufort, that they would be capable of such beautiful work.

One is impressed at the very low degree of stigma reported by the carers. Apart from children staring and giggling occasionally, there was a very heartening degree of understanding and acceptance of the mentally handicapped among the public at large. Carers of the elderly in this study bore this out - they were very understanding and supportive of the mentally handicapped. In fact, one third of the carers of the handicapped said that people tended to fuss over the handicapped more than they would over their normal children.

The Churches and voluntary bodies should become more sensitive to the needs of carers. Up to now the elderly who lived alone were regarded as the main need group in the community. The Churches can point up the

contribution which carers make and enlist support for carers of the elderly. The carers of the handicapped received very few visits from their priests. More support is called for here. The prophetic work of Vanier, which has worked its way upward into the Pope's addresses on the handicapped, must now work its way down to priests and people and throughout the educational system. The Churches can support and facilitate Carers' Associations and stimulate the voluntary organizations to organise baby sitters or minding services, thus giving carers a break. The Churches can lend their support to local Care of the Aged Committees for the setting up of Day Care Centres. A number of religious orders have a very strong presence in the area of care of the handicapped and have developed considerable expertise and now carry political clout for this reason. Coordination of Church, voluntary and statutory services needs to be improved. The central Christian commandment of love of neighbour must be seen to include carers and involve neighbours to a much greater degree than hitherto.

I am not the first Irish cleric to speculate on the motives of carers or, to use a modern phrase, to ask, "what makes them tick?" A parish priest, An t-Athair Peadar O Laoghaire, wrote early in this century and told a story he had heard in his childhood about the days of the Great Famine of 1846.

"But what about Maire Ruadh. She and Larry had a garden.

The blight came on it. I heard her telling how she spent the day, when the stalks were rotting and falling, looking at the garden and she crying, and not knowing in the world where they would get anything to eat.

The garden was no good now. When they'd eaten whatever food was in the house, the hunger greatly affected poor Larry. He got rheumatics and wasn't able to rise from his bed. Maire had to go out "gathering" (as they used to call it) seeking alms. That woman used to go out in the morning and she on a black-fast; and she'd go west to Clydagh, over the hills, for four or five miles of a journey. She had some relations there. A small can of milk used to be given to her there and she'd bring that away home with her. She'd put it on the fire until it was curds and whey. Then she'd give the curds to Larry and she herself used to drink the whey. The woman kept this practice up until poor Larry died. I don't know where there was another "lady" who would have done it at the time. The strong faith that was inside her, it was this which obliged her to do the deed."<sup>19</sup>

I wonder, had the carer been asked why she "carried the can", might she not have replied, "He is my husband, and I love him and there is no one else ... "

NOTES

1. Glendenning, C., 1986, *"A Single Door"*, Allen and Unwin, London, p.200
2. Goldthorpe, J.E., 1987, *"Family Life in Western Societies"*, Cambridge University Press, Cambridge, Ch. 9
3. Hannan, D., and Katsaiouni, L.A., 1977, *"Traditional Families?"*, Economic and Social Research Institute, Dublin, Ch.3
4. Cooper, J., 1986, *"The Penguin Dictionary of Humourous Quotations"*, Penguin Books, London, p.162
5. Hannan, D., and Katsaiouni, L.A., 1977, op.cit., p.85
6. Re Life Histories, Case No 80:  
The mother collapsed and went into a coma at breakfast last October. Her son, Jimmy, placed a pillow under her head, covered her with a rug and went and used one of his three or four words to call a neighbour to come. The mother went into hospital where she is slowly recovering, while the neighbour took Jimmy in to live with his family.
7. Wenger, G.C., 1984, *"The Supportive Network"*, George Allen and Unwin, London, p.193  
"Where family are known to exist in the same community neighbours may hang back or prefer to alert relatives when they are concerned for fear of being seen as interfering."
8. Bulmer, M., 1986, *"Neighbours : The Work of Philip Abrams"*, Cambridge University Press, Cambridge, p.234  
" Why, for example, should that norm (altruism) appear to work as a source of informal care so much more strongly among working class Catholics than amongst most other religious groups? Because it is peculiarly a 'community' religion? Because of the peculiar policies of that particular church in relation to birth control? Or because of the relative social segregation of the social

milieux in which working class Catholics live? One could list a host of possibilities to explain the differential involvement of particular religious groups in informal care and all of them would point behind the norm of altruism to fairly complicated origins and concomitants of informal care mediated by religious beliefs."

9. Hadley, R., and Webb, A.L., and Farrell, C., 1975, *"Across the Generations"*, George Allen and Unwin, London, p.141  
The successful volunteers were more likely to declare some religion than their less successful counterparts.
10. Goldthorpe, J.E., 1987, op.cit., p.140
11. Report of Working Party on Services for the Elderly, 1988, *"The Years Ahead : A Policy for the Elderly"*, Government Publications, Dublin, p.34
12. Lewis, J., and Meredith, B., 1988, *"Daughters Who Care"*, Routledge, London, p.21
13. Moroney, R.M., 1976, *"The Family and the State"*, Longman, London, pp.138-139
14. Report of Working Party on Services for the Elderly, 1988, op.cit., p.44
15. Report on the Workload of Public Health Nurses, 1975, Report of a Working Party, Government Publications, Dublin
16. Report of Working Party on Services for the Elderly, 1988, op.cit., p.183
17. Report of Working Party on Services for the Elderly, 1988, op.cit., p.134

18. Conniffe, D., and Keogh, G., 1988, *"Equivalence Scales and Costs of Children"*, The Economic and Social Research Institute, Dublin, p.xii
19. O Laoghaire, P., 1915, *"My Story"*, translated by O Ceirin, C., 1987, Oxford University Press, p.31

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## APPENDIX 1

### LIFE HISTORIES

As explained in Chapter 4, I included a section on the history of caring in the interview. It was not a full life history but a personal account of how the carer first came to take on the task and of her subsequent experience until the time of the interview.

The aim, in accordance with Malcolm Johnson's technique, was to induce the carers to tell their story in their own words, the interviewer merely prompting them occasionally and keeping them on course where necessary.

The resulting accounts could form a report on their own and Johnson would maintain that they would be a truer account of the reality as experienced by the carers than the responses to the formal questions in the remainder of the interview.

The personal accounts certainly form an excellent background to the study as a whole. Some individual accounts were deeply moving and they gave a deeper insight into the joys and sorrows of caring than the formal questions could ever have achieved on their own. It would appear also that the opportunity to tell their story in their own way for a while helped the carers to speak more freely throughout the remainder of the interviews.

Because of the fact that two groups were being studied, the carers of the elderly and of the handicapped, and the 199 interviews took an average of two hours each to complete, it became a problem to condense the material within the limits prescribed. I should have had to confine myself to presenting a very small sample of the life histories. This led to the problem as to how I should choose a representative sample. Was I to choose the most interesting cases which demonstrate the "highs" and "lows" of the carers?

Considering the problem of space and also the fact that the life histories are a backdrop to the study as a whole I decided to place them in the appendix section. This allows me to present more than one third of the total number and this ensures, on the one hand, that the cases are broadly representative, and yet include all the more interesting accounts.

I made an analysis of the accounts under a number of headings and Tables 1.0 and 1.1. set out the frequencies with which various issues were mentioned in the spontaneous telling of the carers.

The difference between these personal accounts and the other material presented in the body of the text could be compared with that of the water one drinks directly from

a spring and the treated water from the tap. The former has a natural sparkle which is lost in the reservoir and in the pipes. Another reason for keeping the two supplies apart !

I decided not to change names or other details as I regard this report as coming within the terms of the confidentiality which I guaranteed. Naturally, if the material were to go to a wider public a good deal of disguising would have to be done. Some of the most interesting cases would have to be omitted altogether as they would be readily identified in Kerry even in disguised form. So I have presented them without alteration of any kind.

TABLE 1.0: LIFE HISTORY: PATTERNS FOR CARERS OF ELDERLY

	YES %	NO %
Carer always lived with old person	46	54
When old person became feeble, was naturally cast in the role of carer	65	37
Crisis arose in old person's life which forced carer to live with old person or vice-versa	35	65
Carer returned from abroad to look after the old person	7	93
Carer gave up permanent job to care for old person	6	94
Carer praises Public Health Nurse	3	97
Carer praises her husband for the help he gives	11	89
Carer anxious whether she/he can continue with the task	11	89
Carer finding the task increasingly difficult and complaining about it	11	89
Carer expresses intention of continuing caring as long as possible	76	24
Carer expresses negative attitudes to sending old person to institution	13	87

TABLE 1.1.: LIFE HISTORY: PATTERNS FOR CARERS OF HANDICAPPED

	YES %	NO %
Carer found out gradually child was handicapped	67	33
Carer taken completely by surprise by the announcement	51	49
Carer shocked and stunned when told	58	42
Carer unwilling at first to accept child	12	88
Carer angry at the way she was told	14	86
Carer still angry with medical people because of the manner in which she was told	12	88
Carer tends to blame herself	6	94
Carer tends to blame Almighty God	1	99
Carer saw handicapped child as a punishment	2	98
Carer mentions husband as taking it better than herself	6	94
Carer angry with the help medical people gave after the birth	15	85
Carer mentions husband as a great source of support at the time	3	97
Carer speaks of experience as the worst in her life	34	66
Carer has levelled off now	86	14
Carer has grown to love the child	70	30
Carer sees child as enriching the whole family	35	65
Carer sees child as damaging to the family	2	98
Carer worries about what will happen to the child when she is gone	12	88

Now the first case:

CASE NO.1:

Bridie O'Connor, 53 years of age, is single and looks after her mother, Catherine O'Connor, who is 87 years of age.

*"I took my mother's old age when it came. I felt no great emotional strain when my mother became old. Our family is a very close one. It might be different if I was all on my own, but Eileen, my sister, is with me and she is very good. James, my brother, his wife and family just live one hundred yards over*

the road. He is a farmer. They come up a lot to visit us. My nieces and nephews are very good in relating to my mother. They enjoy each other's company.

I suppose when my mother became house-bound I felt a little bit tied down, tied to the house. But as I have a car I can go shopping and go to town whenever I need to. I think when she will die, though she is 87 years of age, I will miss her a great deal. She was very good to us when we were growing up. My sister and I have been happy to look after her. So when my caring task will come to an end there will be a void in our lives. Eileen and myself are not the types that go out a lot. We like to stay at home knitting, reading or watching television. So her presence does not intrude a great deal in our lives. It has been a great joy for us to look after her."

CASE NO.2

Mrs. Noreen O'Mahoney is married with three children aged 9, 6 and 4. Her husband is a farmer. She looks after her mother who is 66.

"I am an only child and I was always very close to my parents. My father died several years ago and I cared for him until he died. When I got married and moved into this new house, I visited my mother regularly and then three years ago I felt that my mother was lonely and depressed and I asked her if she would like to live with us and she agreed and I think she was delighted. I always made up my mind that I being an only child would have to look after my parents, so I don't resent it in any way. My mother is not bed-ridden. She is not a burden at present. The only problem is that she suffers from depression. But she goes to the Clinic and they help her overcome it even if only temporarily. I think it is my duty to look after my mother. She was always very good to me. I don't know if I would feel the same if I had to look after my mother-in-law."

CASE NO.3

Kathleen Crowley is 51. She is married with two children aged 13 and 11. Her husband is a farmer. She looks after her mother who is 90.

"My mother and father had a General Grocery, Drapery and Light Hardware shop in Ardfer. I worked in the shop since leaving school. My father died twenty

years ago when my mother was nearly seventy and still quite capable. I married my husband and I still worked in the shop but not full-time. However, when my mother got a stroke fourteen years ago and though she recovered, I have been looking after her ever since. My husband drives me up in the morning after I help with the milking and I stay here all day. I am completely tied down. I have a ticket for the All-Ireland Football Final and I can't go! I have two sisters, one in Causeway who has a shop, and the other is married in Tralee, but though they both come to see her one day a week, that's it. Anyway, though she abuses me, would you believe she can still give me a clatter across the head, we fight, still tis me she wants. She can be very annoying. She feels she is still in charge of the shop and she comes out to the shop and empties the till. She is very fastidious about her appearance and must have a change of underwear and jumper every second day and rubs Oil of Ulay into her face before going to bed. Sometimes, I feel she'll bury me, I feel so worn out. Still, there's no way I'd put her into a home while I am able to carry on. My brother lives in the house too and he's her pet. He leaves all the bossing to me. I have to manage her when she becomes difficult. I have tried to get my sisters to come more often and even spend the night but they always have an excuse."

#### CASE NO.4

Mary Coffey is 36. She is married with one child and she looks after her mother-in-law who is 78.

"I was away before I got married. I came from South Kerry. I married into this house fourteen years ago. At that time, both my parents-in-law were alive and active. They were well able to look after themselves that time and were able to the first nine or ten years. Then, my mother-in-law became a diabetic ten years ago, but she was able to cope well enough until four years ago. Then she went blind and is on Insulin. I have to administer the Insulin every morning and do tests four times a day on her urine. But my mother-in-law improved and recovered some sight. This pleased me.

My father-in-law had high blood pressure, but was able to do most things for himself. Then three years ago, he got a stroke and he died within two weeks. He was no trouble really but he had to be looked after for five weeks before he died. My mother-in-law is always in the house and I can't leave the house. I can't go out or, if so, only for a

short period. I would not feel happy if she were on her own. I would be more worried if I was out than she would in case anything happened to her. The public health nurse came once to show me how to give the Insulin injection to my mother-in-law after she had come out from hospital. The nurse never came back, but then she had probably done her job in relation to this case. I have never sent for her and I felt I did not need her. My husband has a small garage here in the back of the house and he is always near at hand to help if any emergency occurs. We have a telephone.

I was married for twelve years before we had our one and only child who is now 2 and this has given me great happiness and also has pleased my mother-in-law greatly."

#### CASE NO.5

Maura O'Sullivan, 40, is a housewife and has five children aged 17, 15, 12, 8 and 2. She looks after her mother-in-law who is 85.

"Con and I got married nineteen years ago. When I came into the house after marriage, I did not think of the task of looking after my parents-in-law. I thought that they would be able to look after themselves always. My father-in-law was alive then. I did not realise that it would be so difficult to look after them.

Twelve years ago, my father-in-law died suddenly of a heart attack. Initially she missed him but she came to terms quite well and quickly. About that particular time her arthritis got bad. She then had two operations on her hips and one of them was not very successful.

From the beginning I resented the fact that I was the person who was shouldered with the responsibility of caring for her. Why was I the one when she had five daughters of her own? Each of them could have taken her to their own homes, if not for good, at least for long periods of time. My husband understood how I felt and supported me in my views.

We built a room for her onto the house about five years ago. This was good both for her and for myself. It made each of us fairly independent of each other and I and Con could look after her. I do the

cooking for her and take her up her meals.

In my task of caring for her, I never felt really tired. Con, my husband, is a great support. Our children who are now growing up, look after her quite a lot too and they get on very well together."

CASE NO.6

Jeremiah O'Connor is 66 years of age and looks after his wife who is 68. His son and a brother-in-law live in the house with them.

"Over the past ten years my wife Mary's health began to deteriorate. She got Diabetes and had to go to hospital in Killarney. She neglected it. She didn't take the Insulin every day as she was ordered. When one has Diabetes, there is little healing when one gets another ailment. Mary's leg was burned with boiling water. Her leg got worse and there was little or no healing. Eventually the limb got so bad that it had to be amputated.

I did not feel good about the situation at that stage. It was a great shock to me to learn that my wife's leg had been removed. I was hopeful, however, when I learned that she would get an artificial leg. This hope did not last long. Mary's sight began to fail. One eye gave trouble, and in the end, the sight went. I felt very distressed at that time. It was nothing compared to the distress I felt when she lost all her sight. She was now totally blind. It was then she became totally dependent on me.

I felt that all this would be too much for me. I thought I could never cope. This all happened four years ago now. I never realised how much I was able to do. I began to wash her. Getting her up out of bed and putting her to bed was difficult at first, but soon it came naturally to me.

As time passed, I became more familiar with the situation. I was able to cope. It brought Mary and myself closer together. Our five children rallied round as well. There was a great sense of unity. Maurice, our son at home, is exceptionally good. I thank God for giving me the strength to do what I have to do."

CASE NO. 7

Anne Murphy is 19. She has just finished school and not yet found a job. She looks after her grandmother who is 86 and lives in a house near their own family home. The grandmother lives alone.

*"Joan, my sister, used to look after my grandmother. She was attending Boherbue Comprehensive School during the day and she looked after our grandmother at night, staying with her. When she left school she got a job in Dublin, so Marjorie and myself took turns in going down to stay with her and look after her. Marjorie did the Leaving Cert. last year and left home as well to go to study at U.C.D. I now find myself caring for my grandmother.*

*I did the Leaving Certificate in 1984 and completed a Secretarial Course last year. I am presently unemployed and looking for a job. I find that I have the time for caring for my grandmother. I stay in my own home during the day helping around the house and then go down to her house and stay the night with her. The task of caring is something I grew into. My sisters before me did it so it was natural that I should continue to do it when my turn came. I enjoy it very much. Although she is a great age, 88 years of age, she is still very healthy and very humourous. She can be very funny at times, although she can be very annoyed as well at other times.*

*I think that old and young people get on very well together. I am 19 and she is 88 yet we can discuss and talk about anything under the sun.*

*If I do get a job and have to go away from her, I am going to miss doing what I am presently doing. However I know that she will be well looked after by my father and mother who only live a few hundred yards from her. Perhaps, in time, she might have to move in and live with them in their house."*

CASE NO.8

Mary McGillicuddy is 82 years of age and she looks after her sister, Margaret, who is 74.

*"I came back to Ireland in October 1977. I had never intended to stay here for good even though my brother, Jeremiah, and my sister, Margaret, used to write to me and ask me to come. I spent forty*

nine years in America altogether. I was 24 years of age when I left Ireland and I hadn't much education so I worked with families and then I spent 29 years with a drug company. I was very happy in the States. I had my own apartment and good neighbours, although I kept very much to myself all my life. When I came back here in 1977, I didn't really intend to stay here for good. My brother, Jeremiah, was alive then and there was stock in the farm and Jimmy Nagle, the neighbour, worked here every day and my sister, Margaret, used to do the housekeeping. Things were bearable then. I wasn't here long before things began to go wrong. I was crippled with arthritis and spent a year in bed. I couldn't even touch the floor with my toe. I was barely up and hobbling about when Margaret was taken sick with arthritis and spent some time in hospital in Killarney. My brother, Jeremiah, died in 1984 and that was the beginning of the end for me. Roles were reversed in the house and Margaret left everything to me. I have to do all the chores as best I can with little or no help from her. I have no interest in anything. I regret ever having come back. My doctor in the States advised me against coming back here. He said the damp climate wouldn't agree with me. I am an American citizen and I have nothing to offer and life has nothing to offer me anymore. Look at us here, isolated without a phone. If anything happened to us in the night, we were finished. We are both invalids, but of us having walking aids. I have to pay a Taxi to take me to town every Wednesday to get the shopping. We can't go to Mass, so the priest brings us both Holy Communion. on the first Friday. I have nothing to live for, nothing to look forward to. I am just a 'has-been'."

CASE NO. 9

Maura Kelliher is 59 years of age. Her two daughters have left home and she looks after her husband who is 71 and who used to be a lorry driver.

"James, my husband, was the best in the world. He could do anything with his hands, electrical work, gardening, papering walls. He never smoked or never went inside a public house. We were very happy for a long time. Then, eighteen years ago, out of the blue one day, he started talking at random. He told me I was down the lane with four fellows. He got very hot about it. So I brought him down to Dr. Billy Prendiville and I couldn't believe it when he told me that tablets wouldn't cure my husband, that he had a nervous problem and was suffering from delusions. He was very violent in those early days.

He was very jealous of me. Anybody who came to the house was bringing a message to me from a boyfriend. One warm summer day, I remember I couldn't go out to the bank of the local river with my children because he was convinced I was meeting someone up there. One night, I felt that he was going to kill me as I lay in bed. He stood over me, folding up his sleeves saying, "last week there was murder in Cork, this week there will be one in Kerry".

Eventually, after much persuasion from the local doctor and the local sergeant, I signed him into the Mental Hospital in Killarney. That was after about six years. He has been in and out of the hospital for periods ever since.

When the doctor first diagnosed his condition I just couldn't believe it. I am convinced now that it was only my prayers that kept me going. I have great Faith and that's how I have survived. When it first happened, my youngest daughter was only four. I didn't even have the price of a bottle of milk in the house, but by degrees I got on my feet with the help of part-time work in my uncle's bakery. I put everything into educating my children and they have done well for themselves. But Jim has got very bad now. In late years, he has lost interest in everything, in the house, in the family, though mind you, even yet when I go out he's constantly wondering where I am going or who I am going out with. He has taken a lot now to wandering about at night, looking for tablets and so on. I don't get any sleep. The strain is getting me down. I have had eighteen years of it and I feel I have had enough, especially when there is no cure. He was in the Psychiatric Hospital up to last week-end. When I heard he was coming home my heart sank. Of course I know what would happen, that when he came home he would not be allright but he would not want to go back again. He's in bed now these days. To-night he'll be up again banging doors and looking for tablets and calling for the doctor. If this continues, he'll have to go in again. I am not physically able for it anymore. In fact, if it wasn't for the family I think at this stage I'd leave him inside. But they get upset if he's in there and they are always anxious to have him back home. It's allright for them but it's I who have to suffer and indeed, to tell the truth, when he is at home, I don't get very much support from the hospital. There was a mix-up about his tablets when he came out this time. I was promised over a week ago that the social worker would come to him but he hasn't arrived yet. If all the family leave here I can't stay alone with Jim. I'd be afraid, though he's not as

violent as he used to be. You don't know what to expect, that's the trouble with mental illness. They talk about cancer, but do you know, I think that this is a lot worse. I have had this to live with now for eighteen years and it's just too much."

CASE NO. 10.

Mrs. Maureen O'Neill is 52. Her husband and her last child of three live at home, the other two boys are away at College. Maureen looks after her mother, Mrs. Molly O'Leary, who is 91 and lives with them in their house now.

"About two years ago, my mother got a mild stroke and then, about a year ago, she got another very severe stroke. Because of this, she lost the use of her limbs and also became incontinent and soiled. She lived with my brother in Castlegregory until about eight months ago. He retired here early thinking that perhaps he could look after her. I used to hate to go home to see her, she used to be so dirty and huddled over the fire. I hated to see her dirty. Then about eight months ago, she had to go into Dingle Hospital. She was miserable there and cried all the time. I think that she was disappointed that she should be thrown there and that none of her own would keep her. She has another sister in that hospital and has two other sisters and a brother in Castlegregory. They all advised me that I couldn't manage her at all. They said I was mad. My husband and myself discussed it and we felt that we couldn't leave her there. My brother couldn't manage her any more and my other sister lived in a pub and had a large family. My mother was always very anti-drink and there was no way she'd go there. Mind you, we were never too close. She was in fact much closer to my other sister in the pub, though any time she had been sick it was to me she always turned. In the beginning, she broke our hearts. She didn't want to be here but at home in Camp. Visitors always came to see her, too many at times. Indeed, I find it very hard on Sunday sometimes, when all the visitors turn up together. But the visitors used to be uncomfortable in the beginning because she used to want to go home with them. It frustrated me too because I knew that no matter how much I did for her, changing her, cleaning her, she wasn't satisfied and would prefer to be thrown in a dirty heap at home in Camp. A few months ago then I had to have a break so she spent ten days in the District Hospital. I needed the time to myself and my husband and myself

planned to go away for a few days. As it happened we didn't go because I was in and out to see her every day. She was happy enough for the first couple of days but then the tears all started again. She was delighted to be out and to be leaving the hospital but she thought she was going home to Camp and she was very disappointed to find herself, in her own words, "landed here again". I feel guilty about her as I feel she deteriorated very much while she was there. She was put into a ward with very old people who couldn't talk to her. The staff didn't have time to get around to her and she lost her footing and it was gone altogether as a result. I think she's getting much weaker now. She used to be great company telling stories about the old days and so on. Now she's beginning to wander a bit and her voice is weakening. She used to come out here to the living-room and sit by the fire, but not anymore. Then for a while she'd get out on the chair for a part of the day, but now five minutes is about enough for her. Though the children were deprived of their study room and of many of the family outings which we used to have, they are very fond of her and love to bring in their friends to see her."

CASE NO. 11

Kathleen O'Sullivan is 61. She has four children all grown up and her husband is unemployed at present. She looks after a neighbour who is no relation, Ellen Wellings, 91 years of age and living alone.

"Ellen has lived next door to me for years now. We were good neighbours to each other and even before I started giving her meals, I would do little things for her. Then she got sick a couple of years ago. She was in hospital and one of the nuns wasn't too happy about her being on her own. They wanted her to go into residential care. Ellen was disgusted. She wouldn't hear of it so she asked me if I would help her out. She had nobody else to turn to. She has been a widow for years and has no children. She is from the North of Ireland and, as far as I know, doesn't have any relatives around here.

So I did what was my Christian duty by her and I had no regrets whatsoever. It is as easy to get her a bit of food ready when I am getting it ready for my own family anyhow. Nurse Eager, who lives nearby is a good neighbour too and comes to see her morning and evening. I would describe Ellen as a

very independent woman and though I clean the house for her and get her meals, she likes to go around and do her own bits of dusting and manage her own ornaments. My son, Philip, tends to her front and back garden. She is a British citizen so she gets no help from the State but she gives me a little something for myself."

#### CASE NO. 12

Con Griffin is 72. He is a retired electrician. He has daughters married nearby and his son, Martin, who has a nervous problem lives in the house with him. He looks after his wife, Hannah, who is 74.

"I married Hannah 47 years ago when we were both young, good-looking and full of life. We loved dancing and going to football matches and Hannah was a great camogie player. We hadn't much money as I was unemployed and joined the Army from 1940 to 1945 and was away in Clonmel, Limerick, The Curragh and Rinanna, now Shannon. Then I got a job with the E.S.B. and life was good. We had seven children, but two died as babies and Martin had a nervous breakdown fifteen years ago. He was almost trained as an electrician and he has never worked since. He has been a constant worry to me. Hannah is crippled with arthritis and only walks with the aid of a walking aid. Then, three years ago, she became senile and is now like a child. She keeps looking for her father and mother and I bring her over to the graveyard and show her their grave. She's happy for a while but in a couple of nights she starts all over again and we are off to the cemetery again. Though I have two daughters married near me, I am the person Hannah wants. Anyhow, they have husbands and young families. I retired from work seven years ago and since then, I am always with her. We sleep down stairs as she couldn't climb the stairs, but as we have no bathroom or toilet downstairs, she has to use the commode which I empty. But, through it all, I see her as the lovely young girl I married in 1938. I am glad that I am spared to look after her and I hope I can continue to do so. I take her for a drive twice a day and she loves this. My son, Martin, helps me a bit. He is very moody and Hannah is afraid of him. He has an Invalidity Pension and so he is not dependent on me financially and he looks after himself sometimes. I am afraid that if anything happens to me Hannah will be put into a home, but as she is senile it won't affect her as much as the normal person. This is a small consolation for me."

CASE NO. 13

John Hussey, 71, looks after his brother, Dan Hussey, 76, and another brother who lives with them in the house.

"My two brothers and our sister, Mary, lived here in this little house all our lives. We all worked, except Mary, as labourers and we were very happy. Although we hadn't much money, Mary looked after the three of us and kept the house shining and gave us lovely meals. Then six years ago, Mary gave us the dinner and before we had it finished, she got a brain haemorrhage and was dead in a short time. We got an awful fright, and to tell you the truth, we never got over it. But we carried on as best we could, though we aren't making such a good job of it. I am the youngest and I do what I can to help the rest of them. I try to keep the place fairly tidy but the worst job is the ironing. I manage the washing all right by steeping the clothes and by using hot water and powder, but my ironing is a dead loss. The cooking is tough too but we aren't too fussy. We have five dogs to eat the real bad efforts. I tried to get my brothers not to keep big sums of money in the house but they wouldn't listen to me and last spring, these two fellas came to the door selling quilts. They brought in two big quilts and opened them up to show them to us. When we said we didn't want them they kept persuading us and bringing down the price. When they went away, we found that the bedroom was ransacked and that the £808 that Ned had hidden in the mattress was gone. So, I take their money to the Post Office now but they miss it. It was a great comfort to them to know that they had that security. I don't know if we can keep going. I suppose it all depends on how my health will go, but we all miss our sister and wonder why God didn't take one of us instead."

CASE NO. 14

Peadar O Loinsigh is in his mid-50s and he lives alone with his 82 year old father whom he looks after. Peadar is a farmer.

"I took care of my mother for years. Her eyesight was very bad, and when she died in 1978 my father was just as bad and I have cared for him since. I do everything for him. He sits by the fire all day. I am out from 9.30 a.m. until 12.00 noon and he is able to get around slowly but his eyes are very bad now. He had an operation for a urine complaint and he has a urine bag for two years now.

*It is a life saver for him and I take care of it well now as I am used to it. I was always very close to my mother and father and anything I wanted they helped me along with it. When my mother died, it was a relief as she was suffering and she was almost blind. It was hard looking at her but I am sure she is in Heaven. My father and I have always had a good relationship so it's only natural that I should do what I am doing."*

CASE NO.15

Sheila Kelly is 22 years of age and she looks after two elderly people, both in their eighties. The more fragile of the two is Katie Feirtear who is 81. They live in the Gaeltacht area of West Kerry.

*"I was asked to take on this position of responsibility by the daughter of Katie and Michael because she wanted them to remain in their own home. I see it as a responsible task although I am no relation to them. It is a challenge because I am dealing with other people and I am also anxious to devote myself to the simple things in life. My motive for taking on the job is out of a sense of caring for people. I had experience in a residential home for the elderly in Cork and then I answered an advertisement in the 'Cork Examiner'. Mrs. Ferriter's daughter is a teacher in Dublin and she was looking for a paid Home Help to mind her mother. I took on the job but my interest is not in money. It is looking after old people which I see as a vocation in my case. I am now two months looking after Mrs. Ferriter and I like this West Kerry area very much. I think that we should be looking after old people out of a sense of responsibility love and charity, not just as a duty or as a job. I see my job of caring for these old people as arising from a genuine concern for the old."*

CASE NO.16.

Maria Elizabeth O'Connor is 33. She lives with her husband and four children a short distance away from Hannah: Shaughnessy who is 75 and is her husband's aunt.

*"I came to live in Ireland from Australia about five years ago. At that time, Hannah lived in Kilmoyley, but I didn't really get to know her until she came to live here. When she first came to live here, Hannah's daughter-in-law was caring for her but they were having their tiffs and Hannah began to call on*

me. Then twelve months ago they had a real falling out and she began to call on me more and more, so that it was really like a full-time job for me. Someone like a social worker or a nurse had forms and I filled them out and I was getting £15 a month. I worked right up to the week my last baby was born and then I had to stop going down for a while so I don't get the money any more. Still nobody bothers going to her house and she depends on me so I have to keep calling on her. You see, without me, she has no one to bother with her. To tell you the truth, she is not a very nice person. Her own daughter came home from England and only stayed two days as she couldn't stick it. Her sons don't go near her either. They can't stand the way she talks about people. I don't like it either but I go down there because I feel sorry for her, though if I can go down, why can't they? She went into a Home in Killarney once but came out again. She suffers from terrible depression and the doctor says it's her age. She does nothing all day. She doesn't even watch television. She calls on me at the most inconvenient times. It's her own fault that the neighbours don't call. The people around here are very nice, but she talks about them so they don't go near her. My husband is her nephew and that's how I came in contact with her first. I really don't know how long more I will be able to keep going. Yet, I do feel sorry for her. She is so much alone. But I feel sorry for myself too. Why should I be the one the burden is on and she is not the only old person around here? There are many other old people around here who never have a visitor. Wouldn't it be great if something could be done so that at least they could have someone to call once a day?"

#### CASE NO.17

Theresa Madden is 39. She is married and has four young children. Her husband is a labourer. She looks after her father-in-law, Michael Madden, who is 83 and was a County Council labourer.

"I went to America to work for a couple of years. When I came back, I came down to Kerry to visit my sister who had married a Kerryman and lived in Causeway. As I am from Roscommon, I didn't know anyone from Kerry, but I love the people around Causeway and I met Michael Madden junior. We fell in love and got married and came to live with his parents, Michael and Mary Madden. As that was fourteen years ago they were both fairly young and they made me very welcome. We got on very well with them from the start and they were very helpful to me.

My mother-in-law was a great help to me when I had my children. We never thought of getting a house of our own even if we could afford it. Over the years, naturally, they have become very feeble, and while my mother-in-law is very active, my father-in-law is crippled with arthritis, is totally blind and gets sugar in the urine. I love them as if they were my own parents and I look after them, especially my father-in-law and I hope, with God's help, that I can continue to do so. They are quite happy and comfortable here and when people say, "would you not try to get him into some home, such as that in Abbeydorney?", I get very annoyed. The children love them and they love the children and, please God, they will be here with us until they die."

CASE NO. 18

Hannah Murphy is 61, single and unemployed. She looks after an old lady who is no relation of hers and who could be described as a friend and she is 87. They met at the Community Centre where a lunch for elderly people was arranged each day.

"Nell used to come to the Community Centre for her lunch and I met her there. She invited me to her house and I used to call regularly afterwards. Her nephew, Con, was alive then and we'd all have great crack. He was very good to her and he used to call a couple of times every day. It was a loss to her when he died. She used to have a lot of friends calling then. I feel badly that the Home Help only spends an hour every day with her. I don't think that's enough. I felt badly about it so I spend all afternoon with her. I heat up the lunch she gets from the meals-on-wheels service or maybe I do a nice bit for her myself. She has got very feeble in late years. Her appetite is not as good as it used to be. I call because I am a friend. It's somewhere for me to go to out of here for a few hours every day."

CASE NO. 19

Michael Kirby is 55 and helps to care for Joan Quinlan who is 75. He is a farmer and lives with his wife Noreen.

"When Mrs. Quinlan's husband died, she came back to her own home to live with her brother on the farm next to ours. He died about five years ago, the year she came to him and she was left alone in the

place. The farm is willed to a cousin of hers but he rarely calls to see her. She has no close relations living anywhere near here. She is a very odd woman, but we try to take no notice and keep calling on her as she needs someone to look after her. She has fallen out with a lot of her neighbours. Her sister wanted her to go into a residential home, but she wouldn't hear of it. Another neighbour, who is a Garda, also calls to her and keeps a vigil on her place in case robbers might call there at night. Either my son or myself milk the cow for her in the morning and in the evening and we also do any farm work that's in need of being done. But she never pays us or appreciates what we do for her in the least. Our greatest worry is that she takes a few drinks when she goes to town and often brings a bottle to drink at home. I am afraid that she will fall or that the house will go on fire when she is in this state."

#### CASE NO. 20

John McCarthy is 74 and he is looking after his wife, Catherine, who is 65. Two sons, one 35 and the other 33, live in the house with them.

"We were married thirty seven or thirty eight years ago and we have two sons who have no jobs only drawing the dole. We had a very bad old house, but about six years ago we got the County Council house we are now living in and it is a great improvement. My wife is a terror for the worry as long as I know her. About seven years ago she got very bad with the nerves and depression and she had to spend some time in the Mental Hospital in Killarney. Since she came out, she is on very strong tablets and I'd say only for them we couldn't stand her. She gets very bad depression and when she's down and out she doesn't bother about anything. I have the Old Age Pension but we don't get anything else like the free electricity or coal because of those two useless sons who are living with us. I don't go out much because she misses me herself, but then where would I go? I'd love to go to the Village one or two nights a week and drink a few pints of Guinness with the lads, but I have no way of going and the Guinness is too dear. And I suppose I couldn't leave herself and she couldn't take a drink on account of the tablets. We are together now for going on forty years and I suppose I might as well stick it out and I suppose we might as well stick it out together. But I can tell you, 'tis a tough old life."

CASE NO. 21

Kay Galvin is 70 and she looks after her brother, Humphrey, who is 68. Her sister and nephew live in the house.

"I first emigrated to the United States when my mother died. I built up a nice life-style there. I had a nice apartment and a nice job with a good salary. Then, in 1971, my sister who lived in Fossa got very sick. She had cancer so I came home to look after her and give her children a chance of going to school. I stayed for a while after she died and then I went back to the United States to pick up the pieces again. In 1976, my brother, Jerry's wife died, so I stayed in Ireland with him for six months. They had no children. One day the priest arrived to tell me to come quickly down to Fossa, that Humphrey, my brother, had got a stroke and was very bad. My sister's husband had died before that and her nerves were very bad and she was all in pieces. The doctor thought Humphrey wouldn't live at all. He was in hospital for a while and my sister brought him home. Of course he had always lived with her helping on the farm. I said to myself I'd stay for a year to help them to get on their feet again. I'm still here! If I weren't here Humphrey wouldn't be here. He'd have to be in a Home. I have no home, no income, nothing in this country except two suitcases. I could live like a lady in the United States with my own apartment and my job. I could, of course, walk out but it would do me no good. I'd be worried about Humphrey. He needs full-time care and my sister couldn't give him that as she goes out working on the farm with Denis. All I have is what I get from the United States Social Security. Sometimes it comes monthly and then at other times, its maybe five or six weeks. I have used up all my savings. There in the summer, when things were very bad, I went to the Information Centre in Killarney to see if I could get any financial help for minding Humphrey, but they told me I couldn't. Then I applied for the pension and I was rejected because they said I had a little too much in my United States pension. But I love Humphrey and I couldn't turn my back on him now. Since he got the stroke, his memory is gone and he doesn't talk much and you have to be there all the time. He'd never think of eating or of asking for anything to eat unless you put it in front of him. I don't think my sister could cope on her own. I think she'd go to pieces, so I feel I must stay on."

CASE NO. 22

Jeremiah McGill is 37, has a wife and four sons aged 7, 5, 3 and 15 weeks. He looks after Hannah Keating 72 since he owns a farm next door to hers in a very isolated area near Caherciveen.

"In 1969, I bought the farm next door to Hannah Keatings in Lower Direen. I winter cattle there and so during the winter, I call to the cattle twice every day. I visited Hannah every time I visited the cattle. While I am not very close to her personally, I still feel responsible for her because there's nobody else doing so. The only access to where she lives is access through a strand and so her comings and goings are limited by the coming and going of the tide each day. She goes to Caherciveen every four or five weeks, but she has to be back before the tide comes in. Sometimes she is stuck at home for long periods and then she becomes very depressed and difficult. On the whole, she is a difficult person anyhow. She won't take anything and wants to pay her way completely. You have to be very careful of how you put things to her as she can get very slighted for the least little thing. She's not sick or feeble or anything like that. It's simply that she's living in a very inaccessible locality with no neighbours around and those that are there, are old batchelors nearly as old as herself. Since I visit the cattle there every day, I feel obliged to visit Hannah too, and feel badly that her own nieces and nephews in England never come near her. I think it's sad too. Hannah had a life of her own and probably would have got married and so on only that she came back to Direen to mind her own parents before they died. I am hoping and so are her friends in Caherciveen that she would apply for one of the old peoples cottages near the town which the County Council are building there. Otherwise, I am afraid that the loneliness of her house is going to get her down eventually."

CASE NO. 23

Robert Fitzgerald is 74. He looks after his sister who is 73 and she suffers greatly from depression and is almost all the time in bed and his nephew also suffers from depression and seems to spend almost all the time in bed too.

"I am taking care of my sister for a long time. She is a very nervous person and is in bed most of the time. She gets very depressed. I have two of them in bed every day. My nephew lives with me

and he also suffers from nerves so I have to look after him and I do a little bit of farming to keep me occupied. The district home help visits me once a week and takes my clothes and their clothes to the laundry and it helps a lot. I have another nephew who lives close by and he takes me out twice a week to the pub. He is good to me and calls every evening. I keep on going fairly well, thank God, considering that my sister is so depressed. However life has to go on. I have given up hard work on the farm since I became over 70. I used to love going with the horse and cart in the days gone by. My sister was once away for treatment.

I felt sad then but was very glad when she came back. I manage to come out of every crisis, but getting out of the house is a very important break for me."

#### CASE NO. 24

John Cronin is 60. He and his two bachelor brothers all live together and they help to look after their mother who is 93. They own a small farm.

"My mother had been in good health until about ten years ago when she was 83 years of age. Up to that time she did everything in the house, got our meals, did the washing, but then gradually she became feeble and her sight went. Her memory is very poor also. She tends to forget and keeps repeating the same things. She is able to get up every day for a time but someone of us always stays in the house with her as we would be afraid that she might fall and would not be able to get up herself and might break her hip. The three of us live here in the house with her and we all help to care for her. I do not consider it difficult."

#### CASE NO. 25

Mary Hanafin is 56. She is single and she looks after her mother, Nora Hanafin, who is 90.

"I never worked outside the home, so I was always helping my mother, but it is only in the last five years that I am doing more and more for her. She is now 90 and she can still do an awful lot for herself. The only difficulty she has is with dressing herself. I like to polish the kitchen

tiles and I am terrified that she will slip on them and break her hip or something like that. I also have to watch her with the stairs. Her health is good but she suffers from a hiatus hernia, so I put two blocks under her bed and raised her pillows so that she has more comfort. I am very happy with my life. I wouldn't change anything if I had it to live over again. I like being in the house and I am not sorry that I did not have a job outside. I have no regrets. I love my garden. The flowers are going off now but you should have seen them two months ago. Mother sits in the garden when the days are fine. Other than that she stays indoors. Like myself, she doesn't care much to go out anywhere. She has a slight touch of arthritis in her right hand now and her grip is not as good as it was, so I don't like to see her near the fire. When we have a disagreement it is usually over the price of things. When something is too dear, she gives out to me over it and this annoys me a bit. But, of course, it is my duty to look after my mother and I am glad to do it. I consider myself very lucky to have my mother with me so long and if anything happened to her, I would not like to live much longer myself. You see, that is my purpose in life, caring for my mother and I am happy and content to do it."

CASE NO. 26

Micheal Baiceir is looking after his mother, Molly Ni Bhaiceir who is 81. He looks after his father who is 92 but who does not actually live in the house with them.

"I am caring for my mother and father all my life. I stayed at home on the farm. All the family left home one by one and went to America. I have one sister who teaches up the country and who comes home in the summer. We look forward very much to her visits. I built a new house five years ago. I had the money so I said to myself, "I will make life comfortable for my parents in their old age and for myself when my own old age comes". My father is a little old-fashioned and refused to sleep in the new house. My mother fought with him about staying in the old house, but it was no good so we leave very well alone. He comes in during the day. He's a little stubborn. I never married myself and I suppose I never will now, but I am very happy the way I am. It's a pleasure caring for my mother and father. Long may they live. They are very healthy apart from a heavy cold now and then. I have never felt tied down. They are always looking forward to the boys coming from the United States or my sister

coming from Dublin. They usually come from the States every two years and it's something to look forward to and it keeps up all our spirits."

CASE NO. 27

Nora King is 56 and she is married and has three children now grown-up. She looks after her brother-in-law, Jeffrey King, 63 years of age and an invalid, bed-ridden all his life.

"When I married Denis twenty two years ago, Jeffrey was in the house. He was an invalid from birth. My father-in-law, mother-in-law, Denis, his brother and his sisters looked after him up until then. At that time, I could easily have placed him in a residential home. His own family did not expect me to carry out the task of caring for him. However, I decided that I would try myself to look after him. I found it very difficult in the beginning especially the first few years, the fact that he was totally dependent upon me all the time put a lot of pressure on me. Also at this time, the oldest child was born. The fact of becoming a mother and looking after him added great strain. Anyway, once he got used to me and I got more accustomed to him, things got a bit better. My confidence grew and in time I realised I had the ability to look after him. As the years went by, and the children got older, it has become much easier. Of course, without Denis, my husband, I couldn't carry out all that I do. It is really the two of us that care for him. I would say that Jeffrey's presence has brought the family closer together. Jeffrey has a Disability Allowance but that does not go far nowadays in buying things that he needs between the E.S.B. and the special bed clothes that he needs as well as other things. It can be very expensive. I feel very strongly that some form of State assistance should be granted to people in our situation. I get a great sense of satisfaction from looking after Jeffrey."

CASE NO. 28

Ann McCarthy is 34. She is married with two young children. She looks after her father-in-law who is 77.

"I am a native of Millstreet, Co. Cork. I married Denis junior about twelve years ago. Denis got the

farm from his ageing parents. I knew when I was getting married that Denis' parents would be in the house. I did not mind and I kept an open mind on the situation. But I am afraid from the first moment things were not working out. I think it was the old story of a new woman coming into a house and putting her own stamp on it. Early in the marriage, Denis senior gave over the place and they seem to have slipped back from being involved after that. We did not relegate them to a subordinate position but they seem to have withdrawn into themselves after he signed over the place and they took no active part in things anymore. That was unfortunate.

My relationship with Denis' parents was one of constant quarreling with odd remissions. Some years ago, my mother-in-law became ill and died. Denis, her husband, missed her a lot. I am afraid that the tension between my parents-in-law and myself affected the happiness of our marriage for a time. His resentment got me down and obviously, my husband was torn between loyalty to me and to his parents. During these years, I had two miscarriages and lost a baby six months old. This had a devastating effect on me. There were times I did not know how I could cope with all this. However, here I am to-day with the situation greatly improved. I have great Faith in God and I pray a lot. My husband has an aunt, a nun, and she has come often and she has given us great support. I have come to terms with my father-in-law's mood swings. We are blessed now with two children."

CASE NO. 29

Patrick Breen is 56 and he lives in North Kerry. He lives with his wife and two grown-up children. He looks after Michael O'Sullivan who is 63, a former psychiatric patient who lived first in a caravan and then in a little specially built house, a mobile home, in Patrick Breen's yard.

"Michael O'Sullivan strayed in here about thirty years ago after he had come out of the Mental Hospital in Killarney. He is here since. He had nowhere else to go. Nobody wanted him so I took him in. Do you see that old Roadmaster out there in the yard? He lived in that for twenty five years. It was the local Parish Priest who got after the County Council to build that apartment over there for him. He lives there alone and he is as happy as Larry. He didn't have as much as a box of matches when he wandered in here. Ita, my wife, gives him

the bit of food and when he goes out of here, it will be in a coffin. I wouldn't put him into a Home nor would my children. Do you see that big cross over there by the wall? I brought that all the way from Dublin and when I am put under, that cross will be put over me and when Mick's turn comes he will be buried beside me. I often ask him for a hand around the farm, mind you, and do you know what he says to me? "I haven't time", and maybe he'd be after spending an hour looking up at the sky. That man would sleep the round of the clock. I often wonder if there was a competition for sleeping he'd win it hands down. I am not a religious man and I haven't much time for the clergy, but if more people would take people in off the street, it would be a better country. I bought an old school a couple of years ago and I had plans to turn it into a place where old people around here could spend time during the day for company and maybe have a hot meal and then go back to their own homes at night, but my son took it off me and had other plans for it. I knew a man once who spent forty years in a Home. I was asking him different questions about it and he kept his head down all the time. When I said, "would you like to come back to your own home?", he raised his head for the first time and said, "yes". That made a deep impression on me."

CASE NO. 30

Ellen Moriarty is 40. She is single and mildly mentally retarded. She looks after her uncle, Dan Moriarty who is 83, and another uncle who is 80 lives in the house.

"When I was small my uncle took me in here. I have been here since and I keep going every day doing the best I can."

CASE NO. 31

Betty Browne, 47, married with four children, 16, 14, 13 and 10. She looks after her mother-in-law who is 86 and lives close by.

"When I married, we built a new house next door to the old farm house. She preferred to continue to live in her old farm house and did not move into the new house with us. She's very active and independent and able to look after herself. She had a bit of a heart attack a few years ago, but seems to have

recovered fairly fully. I take her her dinner every day and she gets the other meals herself. Up til now there hasn't been any work involved in caring for her. Her daughter comes in to sleep in the house with her every night."

CASE NO. 32

Nancy O'Neill is 44, is married with two children aged 14 and 13. She looks after her mother who is 86 years of age.

"About three years ago, my father died. Then my mother came to live with us. Until then she had been living in Kenmare with my father and he looked after her. I had no choice but to take her when he died as she could not cope on her own. She is practically blind. The only other choice I had at that time was to send her to an Old Folk's Home and I certainly did not want that. It is hard on her to adjust to her new home and new friends here. She misses her old home and her old neighbours. I find it very hard caring full-time for her as she is very cranky and often goes into a bad mood. She expects everything to be done for her and she doesn't appreciate what we do for her. Our freedom has been curtailed since she came to live with us. All the family can't go out together anymore for a day and at times, if I go out for a few hours, she goes into a sulky mood. I have only one brother and he is abroad, so I have no other close family members to help me out. My husband is very good and understanding and gives whatever help he can."

CASE NO. 33

Mary Houlihan is 45. She is married with six children. She looks after her father who is 90 and her mother who is 85.

"I am an only child and my parents have both lived with me all my life. My father is 90 and my mother is 85. My father and mother enjoyed good health until they reached the age of 85. My father went blind with glaucoma and my mother has become senile. Minding my father is a fairly full-time job and minding both parents can be very hard at times, but I do it because I like doing it."

## CASE NO. 34

Timothy O'Sullivan, 49, single, a farmer, and he looks after his mother, Nora O'Sullivan, who is 81.

"I was the only member of the family who didn't get married. Two of my brothers lived in England for a while, but they came home and live not too far away now. So, I lived here with my mother and father and did a little bit of farming and went to work for odd days for other farmers as a labourer. My father died about six years ago. My mother was fine until about two years ago when she broke her hip. She was in hospital in Cork and had a number of operations. She has to take great care of herself since and won't leave the house at all now as she's always afraid that she'd fall again. Her kidneys have also given trouble and she has swollen feet a great deal of the time. I'm the one who is single and at home. She's my mother and looked after me when I was a child, so it's my turn now. I don't mind though and I don't regard it as any great trouble at all."

## CASE NO. 35

Patrick O'Connor is 45. He's married with two daughters and he helps to look after his first cousin, Hannah Griffin, who is an invalid and living in her own house.

"Hannah Griffin has been kind of handicapped for as long as I can remember. I think she must have got polio or something when she was young. My mother is her aunt and my father and herself were always back and forth across the road to her place doing jobs for her. About six years ago, I returned with my family from England. My father still continued to look after her. Then, five years ago, my father died suddenly and it seemed natural that I had to follow in his footsteps. She has two other first cousins living about half a mile away, but they wouldn't have been able to care for her as it was mainly heavy physical tasks that were involved, especially the turf for the fire. She has a thing about turf. She is never satisfied until her turf is home whether it's convenient for me or not. I get the grazing of her few acres from her. She has nieces and nephews in England and if she contacted them in the morning to help and to take over her land, I wouldn't mind at all. She's her own boss as far as her land is concerned. She is able to do all her own jobs inside the house. She has visits from the social worker and from the St. Vincent de Paul Society and she goes to Lourdes on

*pilgrimage and she goes to Ballyhunion for old folks' and sick peoples' holidays. She does worry about her turf though and that's my main concern as far as Hannah's care is concerned."*

CASE NO. 36

Noreen Spillane is 42 years of age. She has four children and she looks after her mother-in-law, Hannah Spillane, who is 77.

*"I married Tim six years ago. My mother-in-law was in the house. We could not have got on better. She was 71 then. Her health was good. Since then, her health has failed a little. She has a weak stomach and she's on tablets for her heart. Her illness had no negative effect on me. I was glad that I was, and still am, able to help her. She can do a lot of things for herself. For example, she can still make a cup of tea. Tim and I have four children and looking after my mother-in-law does not in any way interfere with bringing up our children or looking after them. In fact, she is a great help to them. She talks to them and they get on very well with her in the kitchen where she can mind them and keep them from the fire. She is a religious person and prays for us all. She has brought me and all the family closer to God and to one another. She is a unifying force in the family. I admit that I am a very busy person but I enjoy every minute of it. I don't regret that she's in the house. I hope to continue looking after her with the help of God."*

CASE NO. 37

Eileen O'Riordan is a Home Help and receives a Home Help Allowance from the Southern Health Board. She looks after Michael Manning who is 87 and no relation.

*"I had been caring for my own father at home for many years. When he died last year, I realised that I would have to get a job. I saw an ad. in the paper and having come and got an interview, I got the job. I see it simply as a job. I don't know how long I will stay here. It depends on how I get on. I have been working here now for seven months and I'll do my best and see how things work out."*

CASE NO. 38

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Tim Canty is 36. He is an unemployed welder and is separated from his wife and family. He and his mother live at his mother's home. His mother is 81 years of age.

"About eight years ago I came back from England on holidays. My father was dead at that time and all the other members of the family had married and moved out. When I came home, I didn't intend to stay at home, but there was no one else here at home with my mother, so I stayed with her. At that time I got a job as a factory worker in Tralee, but became redundant after three years. My mother's health was good at that stage and she was able to look after herself and cook the meals. Gradually however, her sight got poorer and poorer. I worked for another two years here in Listowel, but now I am unemployed for about the last three years. Because of her poor sight, my mother needs a lot of care. Our next door neighbour cooks the dinner for her every day. It would be great if she could get a home help. Our only income is my mother's Old Age Pension and my dole and it's hard to run a house on those two small allowances."

CASE NO. 39

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Betty Dennehy is 35 years of age. She lives with her mother-in-law, her husband and five young children. She looks after her father-in-law who is 80 years of age.

"When I married Sean in 1974 I came into the farmhouse where his mother and father lived and still live. At that time, both of them were in very good health. My mother-in-law is still quite healthy. After two years of our marriage, Sean inherited the farm from his father. I feel that that was the time when a change came in my father-in-law's life. Until then, he was the one who made the decisions and felt responsible for the running of the farm. Now, he seems to have felt out of things and began to suffer mentally and physically. Mentally, he suffers from delusions and depression. At one stage, he got pneumonia and every spring he goes down with bad colds. He also developed a heart condition. When this change began to take place, I got upset and worried. It was all very new to me then. Our two older children were born at the time and this seemed to have been a great responsibility to me. I felt that if his condition got worse, I would not be able to cope with him at home. But the support of my husband, Sean,

and my mother-in-law helped me to cope with his condition. His mental instability upset me. His wife was the object of the mental persecution he went through. He gave out a lot to her and there was no basis or foundation to this. This phase seemed to pass. Now he is very forgetful and confused. I even tell him something and in five minutes he has forgotten it. Over the years, I have got very attached to him and I am enjoying looking after him."

CASE NO. 40

Marian Wallace is 31. She is married and she has two children, 9 and 6. Her husband is a foreman with Kerry County Council. She looks after Mary Casey who is 76 and is no relation.

"The lady next door was looking after Mary Casey for some time, but her own health failed and there was nobody to look after her. Three neighbours were approached but they refused. I said I would give it a try and I am still looking after her. Mary Casey has been widowed for many years. She moved in to live with her brother and sister-in-law but they didn't hit it off, and when these bungalows were built about six years ago, she got one of them. She has a son and daughter married in England and they come home to see her every year. She is very independent and loves her little house and is quite happy in it. But she loves to feel I am near, that she can either call me herself or send a child across to me if she wants me. As I live almost directly across the road, I don't find it too hard, but I am expecting another baby in January and I hope I can continue with it then. Mary has got used to me now and I have learned to time her and it is hard for an old person to adjust to a new person. But she would do anything rather than go into an Old Persons' Home. On the other hand, it is a job. I was asked to do it. I agreed to do it and I receive £56 a month from the Health Board as a Home Help in this case."

CASE NO. 41

Mary Grady is 63. She is married and her family have grown up and left home. She looks after her husband, James, who is 79.

"About ten years ago, my husband had an eye operation

in London where he was at the time. His eye could not be saved however. Then, about four years ago, his second eye started to give trouble. He attended a doctor in Waterford and in Cork, but the doctors couldn't operate in case he might lose what little sight he had. Now, he's almost totally blind except for a slight glimmer. He gets very depressed sometimes and very irritable. It must be very hard to be blind. Sometimes, I get very irritable too and then I get sorry because I think he can't help it. He's very independent around the house here. He knows where everything is. He can put on his clothes and feed himself and so on. Everything he can do for himself, he does. I'd never manage only for my son and daughter-in-law who live less than a mile away on the main road. They run the farm and call here to me twice a day. My daughter-in-law brings the children over after school every day and that gives my husband great consolation. It takes him out of himself. They also bring him down to their own home every week and that's a great help to him and to me as well. I don't take any notice at all of it. I was brought up that way, to care for the sick and the old, so I don't think much about it. I just take every day as it comes."

CASE NO. 42

Joanna O'Donoghue is 77 and she looks after her husband, Tim, who is 79.

"My husband, Tim, was always a very active man. He worked very hard like the rest of his generation during his life time. He mowed acres and acres of hay with a scythe when he was young. He was a farmer. He cut a lot of turf as well. In his youth, he used to compete in races at sports. He was a good runner and competed in sports all over the countryside. About fifteen years ago, he began to get stiff and arthritis set in. As time went by, it got worse and about nine or ten years ago, the situation got so bad that he became confined to the house. Then, he was able to do very little for himself. He began to lose interest in things. This began to put a lot of strain on me. I spent a lot of time looking after him. It took me a while to get used to it. Now that he was unable to go out and do his usual work and do the jobs he was accustomed to, he began to suffer from mood swings and became very irritable. He was hard to time. This added to the severe pain of the arthritis and made life miserable for him and also, to a certain

extent, for me. Naturally, I felt very much for him. It upset me very much to see him suffering. However, as time went on, I grew accustomed to the situation. The medication he takes eases the pain somewhat. Also, I have great Faith in God and Our Lady. I pray a lot. I am also blessed with a very good family. Patrick, our son, is single. He lives about a hundred yards from us and does everything for us. Nellie and Joan, our daughters, are married and living a few miles away. They come over very often. I have a son, John, in England. He writes a lot and comes every two or three years. Although we have a heavy cross with Tim being struck down with arthritis, I thank God for having given me the strength to keep going."

CASE NO. 43

Joanna Moriarty is 48. She is a widow and she has four children, the youngest, an adopted boy aged 2½. She looks after her mother-in-law, Mrs. Bridget Moriarty, who is 79 years of age.

"About ten years ago, Mrs. Moriarty lost her independence. She developed arthritis and uses a stick. She is a very heavy woman. When she first got ill she had to go back to the hospital. But she was only there a few weeks when she was anxious to come home again. She stayed here then for a while but soon wanted to go back to her own house. Then, she had to have treatment in St. Finian's Hospital as she thought we were trying to poison her. She was very good for a while after that, but since, she doesn't seem to know where she wants to go, hospital, here or her own home. That will all have to stop as it has become very aggravating. She is more than welcome to stay here as we have room here now, but I can't stand any more of this chopping and changing. I don't mind looking after her really. I think people have a duty to their mothers-in-law. After all, she was very closely related to my husband and she is my children's grandmother. I think if I didn't look after her, I'd have it on my conscience. You often find that people who don't look after their mothers or mothers-in-law often suffer from guilt after the parent or parent-in-law dies. She has no other relations around Caherciveen. She has four daughters and two sons in England, but they are no good to her. I felt it unfair at first that I should have to do it when they were there. We contacted them and they were all ringing to find out how she was and they all said they'd contribute money, but nothing ever came of it. We realised

then that we'd have to do it ourselves. Her neighbours in the East End are very good to her but they only can do so much. My husband died last year. Herself and him didn't really get on very well. He used to be trying to talk sense to her, but, of course, she didn't like that. He was a very good man and very good to her, and like in a lot of cases, she preferred a son in England who was drinking and never did anything for her. I have pity for her though, and I think she is sorry now that she didn't get on better with my husband when he was alive."

There were two or three cases in which the interviewer found that the cared-for person had gone to a long-stay hospital or to a Home for the elderly. In these cases, the interviewer went on with the interview, but they were not coded or counted in the study. However, they may be of interest in their own way to this study, even if not included in the statistics.

#### CASE NO. 44

Maureen Flynn, single, 39, a Primary School Teacher, was looking after her mother until a few weeks before the interview. Her mother is 72.

"My mother was brought up in a shop and when her father and mother died, she took over the shop, a general grocery store. My father was a farmer and when they got married my father moved into the house attached to the shop. They had three children, my two brothers and myself. I became a teacher. Nine years ago, my father decided to give the farm to one brother and the shop to the other. So I suppose my mother didn't fancy living with a daughter-in-law, so my father and herself bought a house across the way where they retired. My mother was only 63 and she missed the shop and the company terribly. She became moody and silent. Then she got hardening of the arteries and began to get senile about two years ago. She had to be minded, so my father stayed with her until I came from school each evening. Then, a month ago, she slipped in the kitchen and broke her hip. It is not knitting properly and so she is now a complete invalid and has gone completely senile. We had no choice but to take her to a Home for the elderly when she left the hospital. But she seems happy there as she doesn't know any better. But if she wasn't senile there's no way she'd go into a Home. I have suffered from deep depression myself since I was 24 and was a patient in a psychiatric hospital in Cork for a few months. I am on very strong

*anti-depressants at the moment so I am afraid that looking after my mother and teaching thirty six-year-olds was not on, though I know I was criticised by my neighbours."*

CASE NO. 45

Patrick O'Regan who is 72 was looking after his sister, Kitty O'Regan, who is 82, until some weeks before the interview, when her house which was nearby, was burned. She was burned as well - she received facial burns when she fell against an electrical fire and was taken to hospital. On leaving hospital, she stayed with her brother for a short time and then she opted to go to the Old Folks Home in the town, but with the definite intention of coming home when her house is done up.

*"My sister, Kitty, lived here in Killorglin until she was about forty. Then, she went to Manchester where she had a niece at the time. She worked there as a companion to two old ladies. Then she got a very bad bout of shingles and she never recovered fully from these. She returned to Ireland fifteen years ago. She lived alone here in the town. She never really enjoyed good health after her return home. She sat down too soon. She was very fond of herself. She stopped moving out long before she needed to. She could have remained active much longer, but she maintained an interest in life, she kept up her appearance. She would do her face up and look well. She was fond of reading, read the papers mostly. She was very keen on the Royal Family and in their movements and she kept up with these in the papers and magazines. Then about a month ago, she had a severe fall against an electric line. She was burned and taken to hospital. She stayed with us on her release but was most anxious to be independent and could not go back to her own home for the present but went to St. Joseph's of Annecy Home here three weeks ago. It's just a quarter of a mile from here. She has numerous visitors there and is glad to see them. She was always complaining while she was at home. She was always talking about her pains and aches. But since she went into the Home, she has no complaint except that they get up so early in the morning, 7.30 a.m. I have been working to get the roof on her house recently. At the back of her mind, I think she intends to return home when she is well enough to do so. She convinced herself at one stage some years ago, that she had cancer. She didn't like visitors because she said they came at times which suited themselves, not at*

times which suited her, so she closed her door to visitors for the last few years. She got more and more odd, culminating in the fall and the burning. I myself enjoyed going up there evenings to see her. I met many people on the street as I went up and chatted with them, heard the news and brought the news to her. She was always keen to hear what was happening up the town. I think that in a few months she will certainly be doing her best to come back and I will have her house ready for her, if she is well enough to come back.

In between the time we picked our sample and the time the interviewers were selected, trained and got to the homes of the elderly, about a dozen had died. We had instructed the interviewers that, in such cases, the interview would still be of interest, provided that the carer was willing to give the interview and that it wasn't in any way upsetting for her/him to do so. The result is that we have eight interviews with carers who had recently lost the person they had cared for. These too, I think, provide some interesting information.

CASE NO. 46

Kathleen O'Dowd is 49, single and looked after her mother, Mary, who was 80.

"I was working away from Ireland for many years. I worked in England and in the United States. Then about sixteen years ago, I came home on holiday from the U.S. and I figured that, as I was the only unmarried daughter, it would be best for me to get a job in Dublin, just to be near my parents in case they needed me. There were nine of us in all in the family, but, by this time, Mam and Dad were alone in the house. I visited them at week-ends and whenever I was needed. But they never asked me to stay. My father died ten years ago and my mother seemed to go down hill from that time on. When my father was dying of emphysema, I came home for good to help my mother. My mother suffered from bronchial asthma, so then she got shingles and finally diabetes. We lived together, just the two of us, for ten years before she died on the 25th. June 1985, and those were the happiest years of my life. We didn't even have a television set and there weren't enough hours in the day for us. It was only in the last four years of her life that she needed full-time care and it was in the last seven months that

she became an invalid. Then I got a wheelchair for her and was able to wheel her out down the road when it was fine. She got a stroke and was confined to bed for the last week. Yes, I gave up my job, but I would willingly do it all over again. It was a pleasure to do things for her. She never spoke ill of anybody and she never wanted to put me out. If she wet her nightdress, she would hide it from me so that I wouldn't have to change it. "I'll be the death of you, Kathleen", she used to say to me. If only I could have her back. I would willingly do it all over again. I have no job now and I am all alone at 49. But I hope to get something shortly because it would be a waste of life for me to stay here doing nothing. Surely, there is someone else who needs someone like me to care for them."

CASE NO. 47

William Duggan is 80 and he was minding his wife, Mary, 78, until she died in February 1985.

"She was a kind of invalid for years. Her hips were very bad. You could hear the bones creaking. She walked with a frame and I was always afraid she would fall. The doctor wanted to put her to hospital but she wouldn't hear of it. She wanted to die in her own bed and be 'waked' in her own bed like her ancestors before her. I would never have forced her. I did the best I could for her as she was always a good kind woman. My daughter came a few times a week to help me. All my neighbours were good too. She was a great woman for praying. I often woke up at 2.00 in the morning and I would say to her, "What are you talking about?", and she would say, "Will you stay quiet and let me say my prayers". Do you know who was very good to her too? Fr. Corridan. He is dead now too, God rest him, and buried in Knocknagree. He brought Bishop McNamara to see her when he visited the parish and the Bishop was looking out the window at the view right here from the top of the hill. When he left, I said to her, "Faith, Mary, he won't have a view like that in his place in Killarney". Oh, I tell you she was a holy woman. That television would be cut off short the minute she thought there was something not nice in it. She died in February and, as sick as she was, I would have preferred if she had lived on. When she was here I was always on the go, bringing her a drop of water or something else and that kept me going. But, most of all, I had her company. I tell you I miss her sorely. 'Tis a fright to be on your own. The day drags on and on. I have a

son, Teddy, but I never know where he spends the day or when he will be in. There is no one like your own life's partner. She was always good to me in life and I was inspired above all at the way I was able to keep going at the end. It was a good thing that she kept up the tradition of her ancestors and died in her own bed and was 'waked' in her own home just as she wanted it."

CASE NO. 48

Eugene Murphy is 63 and he looked after his mother who was 90 who died some weeks before the interview in January 1985.

"I left Ireland in 1953 for England and came back in August 1973 for good. I loved England and had a steady girlfriend there. My mother was always writing to me to come home. So when I came home on holidays in 1973, my father signed the place over to me. My sister didn't marry until she was 29. I always thought that she would be the one to look after my mother, but then she left, and I knew it was up to me. I was sorry to leave England. I loved the place and there was plenty of work there. My father died in April 1974 and I bought out the house. I made improvements, put in hot water and a bathroom. I think it is very important to be clean. I had worked with the disabled in England so I knew what old people needed. I cut the legs off the bath and put in a low toilet, so I had the place ready for my mother when she began to fail in health. She was agile up to about 88 years of age and then she began to go off. She didn't get a stroke or anything. I suppose it was old age. The public health nurse was a great help. There were things she could do that I, being a man, couldn't do. You see, she was losing control of herself. She hated hospitals. I remember I had to go to hospital myself for three weeks and she went to my sister then. I wasn't in the door home when she was hot on my heels back into the house. I knew what she liked. When my sister would come around to the house and make tea, she would no sooner be gone out the door when my mother would say to me, "Make a proper cup of tea there, Eugie". I loved making her meals. She was very comfortable. I put in a wall heater for her and would put hot water bottles in her bed because her circulation was bad. When my father died I put in a television. She said, "Don't bring that thing into the house", and I declare to God, after a while, she knew every programme and when it was going to be on. She'd

say, "Turn up the television, Eugie, Garda Patrol is on". She died on the 11th January 1985 aged 90, and I'm on my own again now. I won't go back to England anymore."

CASE NO. 49

Eileen Condon is 35, single but engaged to be married. She looked after her mother who had died shortly before the interview took place.

"My mother had polio when she was three years of age and, as a result of that, one of her legs was crippled and she used a crutch. Still, she and my father were very happy and they had two daughters and one son. My brother, Jack, worked in the building trade and I had a job in the old peoples home, called Fatima Home, Tralee. So even when my father died, we were fairly happy. My mother was able to do the housework, the washing and a bit of gardening. Then four years ago, her health got bad and I decided to give up my job and look after her. Now that she is dead, I am very happy that I did so. We were very close and she loved having me around. I tried to get a little allowance for looking after her, but, thought I went to the doctor, the Health Board and the County Council, I wouldn't get it. I don't know why because I did everything for her. I wouldn't get the dole because I wasn't available for work, so I managed as best I could on my mother's pension and what my brother, Jack, gave me. My mother had every bit of comfort that I could give her and I have no regrets at all. I am engaged to be married, but would not get married while my mother needed me. My fiancée and myself are going to be married in October and I hope that we'll be as happy as my parents were and that I will be lucky to have a daughter to look after me as I have looked after my mother."

CASE NO. 50

Joan O'Connor is 51, married with five children, the youngest of whom is 11. Her husband is a farmer and she was looking after her father, James Daly, until a few months before the interview when he died.

"I am married with twenty six years and my father has lived with us all that time. Since I can

remember, he was suffering with arthritis. He always had difficulty in tying his shoes, but he worked on the farm when he could and he fell in with the family in every way. He was a mild man, not given to complaining, so it was easy to get along with him. I was the only child so the relationship was there and I feel that it is half the battle when the bond is there. There was a patch when I had it hard. When the children were young, they would get on his nerves. They'd be playing around the kitchen and he'd want peace and quiet. You know how it is with old people. As I said, I was an only child so he wasn't used to a lot of children in the house. He would reprimand them and they would just ignore him and I would want to keep the peace. I knew the children had to play. He would complain them to me and they would complain about him to me. So you see, I was torn between all of them. These times were very difficult for me and I felt up tight and I must admit that, at times like that, I wished that he wasn't in the house. That's as far as it went. I would never have put him into a home and he hated hospitals too. He would never have liked to end his days there. When he was getting feeble towards the end, the children were very good to him especially Pat and Sheila. He is dead three months now and we miss him. Looking back over the years, I am glad I was able to care for him. If I hadn't, I would have felt I had missed out. One thing I must say about him is that he never minded see me go out. In fact, he liked to see me go out, not like more who would be cribbing all the time. He was easy to please in that way."

CASE NO. 51

Kathleen Evans is 57 and married with one son and one daughter living with her at the present time. Her daughter is 16½. She looked after her father-in-law who died six months before the interview at the age of 97.

"When I married here in 1958, both Mr. and Mrs. Evans were living here and both quite active. After she died, I had to take over the responsibility of caring for him. He was no trouble. He could do most things for himself. We all miss him now that he is gone and I have lovely memories of him. He was great company for me here in the house. He was lovely to have around and so was Mrs. Evans. They were a lovely couple."

CASE NO. 52

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Eileen Lawlor is 37 and is married with two children, 9 and 8. Her husband is a farmer. She looked after her mother-in-law who died at the age of 75

*"This was my mother-in-law's old home, where she lived with her husband and reared her family. When I married her son, I came to live here and it was only natural that my mother-in-law should come to live with us. There was no question of a granny flat or anything like that. We all lived together and had our meals together. That was ten years ago and even though she was only 65 years then, she wasn't too well, at least she pretended she wasn't and I took over the work. She had diabetes for years and just wouldn't do what she was told. She would eat sweets behind our back and would put sugar in her tea. She was very lazy and I would even have to wash her face. I was very fond of her though but she acted childishly and wouldn't go to bed happy unless she had a row with my husband every night. She slept a lot in the chair. In fact, I think she was rather lazy. She loved to come with us in the car shopping or even going on holidays. She always collected her pension herself. That made her feel good. Although she was a bit contrary we all loved her and we miss her a lot. The children are heartbroken after her and my son's asthma flared up badly after her death. She died very suddenly and very quietly sitting in the chair. It was lovely that she finished up in her own house and in her own chair."*

CASE NO. 53

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Sheila O'Connor who is 48 has a son, Paul, who is 5. She lives with her husband and nine other children, the eldest of whom is 21 and the youngest is 6.

*"When Paul was born the nurses felt there was something wrong with him. The doctor told me to take him to a specialist in Cork. He told me that he thought the child was normal and told me to bring back the baby after six weeks. At that meeting then he told me he thought the child was normal. I had my suspicions all the time as I felt he wasn't quite normal, but, of course, I didn't want to hear it confirmed. He was nine months when I realised that he wasn't as he should be. I already had nine children and knew what to expect from a normal child."*

The district nurse confirmed that he was handicapped when he was one and a half years old. The doctors never told me anything. The social worker from Beaufort called and said if I took him to Beaufort they would do therapy on him. I took him a few times to a speech therapist. When we started thinking about school I didn't want him to go into a residential home. I was hoping that I could keep him at home and get him into a day-school. We went to Lixnaw school to find out if they would take him. They did and he started school there last September. But the transport to Lixnaw is a big problem as we have to bring him to Castleisland which is five miles away where he gets the bus and then we have to collect him each evening. Getting to realise that he was handicapped was a slow process, but I was able to accept it better that way than if I had been told outright in the start. I got used to it gradually. I was very down and out about it first but that wore off after a while."

#### CASE NO. 54

Elizabeth Griffin is 50. Her daughter, Olivia, is 9. Her husband is a farmer and she has five other children, all under 15, living at home.

"Olivia was very small when she was born, 4lb. 4oz only. She was in an incubator for two days after the birth. When she was six days old, I brought her home and she was slow to drink and she got a lot of sickness when she was a baby. She put on very little weight and when she was five months old, I took her to a child specialist in Limerick. He told me she was Down's Syndrome. It was the biggest shock of my life. It was an awful feeling for my husband and myself. We had to come home and tell the other members the bad news. But, we said we would do what was best for her. When she was nine months old, after a long discussion with the doctor, we decided to send her to Beaufort, but we would not leave her there. When she was four years, she stayed in Beaufort for a few weeks of the holidays, then when she was six we sent her to Beaufort school. We had a lot of difficulty in getting the transport for her to the school. She comes home every night. She is very happy in the school and she loves it. Her speech is improved and she has learned to do puzzles. She has also improved at using the knife and fork at meals. I felt very sore that I left the maternity hospital when she was born and that I was not told that she was handicapped. She was five months when I was told it. I did not know where to turn for

help at that time. Now, we have a Down's Syndrome Association which helps mothers and mothers should be told about this association before they leave hospital in cases where children have this handicap."

CASE NO. 55

Nuala O'Connor is 47. She is married to Denis who is a farmer and has three other children, one daughter and two sons. Her daughter, Nuala, the handicapped child, is 8 years of age.

"When she was about six months, I realised there was something amiss. First, I noticed that she had no balance to sit up. She was one year and nine months when she walked and was slow talking and slow at everything. She was over three years of age when we took her to a specialist and he ordered us to take her to Limerick for tests. It was my own local doctor who told me the results of those tests. He said that she was moderately handicapped. When I heard this I was stuck to the ground. When I told my husband, he was dumbfounded. For many nights, I cried myself to sleep and woke up crying in the morning. Eventually, we got used to the idea. She was almost six years of age when she started school and is very happy at the school in Lixnaw and is progressing well. She comes home every night and we have settled down now."

CASE NO. 56

Martin Lynch is 64 years of age. He's a farmer, a widower and he looks after his daughter, Bridget Ann, who is 19. His son who is 23 years of age lives with him as well.

"When she was about four years, we noticed that she was a bit slow but thought she might pick up. She went to the national school until she was six years. She wasn't doing any good there and the school doctor recommended that she go to a Special School. Then she went to the Special School for the mildly handicapped in St. Joseph's, Tralee for one year. At that time then, Lixnaw school opened and she was thought to be more suited there. That is a school for the moderately handicapped. She goes and comes each day from Lixnaw. She had attended that school until last year when after discussion with the Lixnaw school teachers it was

decided that the St. John of God Workshop in Tralee would be the next step. This was arranged so she goes to the workshop each day now. My wife died just twelve months ago and, naturally, if she were here, it is she you would be interviewing and not me."

CASE NO. 57

Wendy Hardy is 51. She lives with her two daughters, one 22 and the other 10, and with her husband. She looks after a foster child, Wendy Grayson, who is 8 years of age.

"I had two short-term foster children and they were sent back to their parents. So then I rang the social services to see if there was any other child that needed fostering. They told me about Wendy who is handicapped. She was seven weeks old then. She was about to be sent to a residential home. The nurses then brought her to me. There has never been any contact with her parents as her mother rejected her at birth. We have never regretted taking her in. She is one of the family now."

CASE NO. 58

Cora Roche is 43. Her daughter, Carmel, is 8½ and handicapped. Her husband and two sons, aged 17 and 15, are living with her.

"Carmel was two hours old when they told me she was handicapped. My first reaction was to put her into a home immediately. But that only lasted for half a day. But then I had a great fear after that that she would die because she had a murmur in her heart, so I prayed that God would give me the health and strength to look after her and would keep her alive. I had blood pressure brought on by anxiety and the doctor tells me it is caused by the terrible fear I have that if anything happened to me, Carmel would end up in an institution, and I cannot bear that thought."

CASE NO. 59

Breda Moynihan is 36. She has two other children, 14 and 12, and her husband is a clerk with the County Council. Her handicapped daughter, Sheila, is 11.

"Sheila was perfect when she was born. It was very sad what happened to her. I was in town one day and it was very hot. She was four and a half months old at the time. I left her in the car in her carry cot while I was doing my shopping. I must have been away for two hours or more and there was no window opened in the car. When I came back she was almost blue. She was rushed to Cork where she nearly died, then they told me she would be retarded. Of course, I nearly went out of my mind. I couldn't sleep at night. I prayed and prayed. Then we could do nothing about it. We had her in the Home for a couple of years and the nurses there asked parents who felt they could bring them home to do so. We brought her home from Beaufort two years ago and she has settled down very well at home. I sometimes wonder if it was the fact that I left her in the car was the reason at all as I have a brother who has a child now like Sheila. But we are very happy with her now and we wouldn't part with her for the world."

CASE NO. 60

Nora Kelly is 57. Her husband is a retired builder and she has nineteen children, six of whom are still living at home and dependent on her. Lawrence, her handicapped boy, is 17.

"I can remember the day well when I first thought there might be something wrong with Lawrence. He was about three years of age, not toilet trained and always clinging to me. I sat him down at the table and he was crying and Eamonn, my son, who was home from the Teacher Training College in Dublin said, "Do you know, mother, I think Lawrence might be retarded". From that moment on, I knew. I sat down and cried my heart out and from then on, I accepted it. Looking back, I must have been suspicious for a long time. I thought he had a short neck when he was born and I said it to my husband but he said, "nonsense, woman". Lawrence was a very quiet child too when he was a baby. He has a congenital heart condition and a kidney

infection which I discovered myself. He didn't walk until he was two years old and he didn't sit up until he was one. But I put all that down to his heart condition. I asked my doctor about him and he told me nothing. By this time, I had eighteen other children and my day was a long hard one. I didn't have time to think. I had a daughter who was deaf in Dublin and the nuns there told me to bring him up there to be assessed. He was assessed by a psychologist who told me that he was somewhere between moderately and mildly handicapped. I had him assessed in Lota in Cork and they told me much the same. When he was five, Mother Fatima at Beaufort wrote to me and told me she had a place for Lawrence in the residential home in Beaufort. The doctor in Lota had told me that if I could keep him at home with my large family it would be very good for him. Mother Fatima had felt sorry for me because I had such a large family, but I decided that I would do what was the best for Lawrence and that was to keep him at home.

Then, a few years later, I was at a meeting one night and that changed my life. It was a meeting of the Parents and Friends of the Mentally Handicapped held at the Arbutus Hotel, Killarney, and they suggested the setting up of a day school. Everybody thought it was a good idea. They got to work on it. He was six then and he was in the day school at Beaufort by the time he was seven. He is now seventeen and he will be leaving the Beaufort school and he will be going to the Workshop either in Killarney or Tralee. He is better than I ever dreamed he could be. There is nothing he cannot do around the house and I am delighted I made the right decision to keep him at home."

#### CASE NO. 61

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Della Doyle is 29. She is a housewife. Her husband is a farmer and she has two other children aged 8 and 3. Her son, John Paul, is the handicapped one and he is 5.

"The one thing that I regret is that I wasn't told there was something wrong with John Paul when I was in the hospital. He was about five months old when I suspected that there was something wrong. The strange thing, once I was told about it, I accepted it straight away. My own doctor told me all about Down's Syndrome and I had no hesitation in accepting John Paul just as he was. I feel

special, like just as if I was chosen, you know, singled out. He is a special child, a gift from God. When he was twelve months old, my doctor told me that the best thing I could do was to have another child as the chance that I would have another handicapped child was very slight. When he was two, Monica was born and I found out that the doctor's advice was right, because as Monica began to do things, John Paul began to imitate her. When she began to eat with her fingers, he began to use his. Please God, nothing will ever make me put him into a residential home. As long as I have my health I will look after him."

CASE NO. 62

Nora Herman is 41. She is married to a factory worker and she has five children, the eldest aged 18 and the youngest 14 and then, Brian, her youngest son, who is 3½.

"I was 37 when I became pregnant with Brian. It was a great surprise as the youngest was twelve.. But we were delighted and the children were delighted and they told all their friends they were getting a new baby. When he was born, I thought his head looked large and I said this to the nurse. The doctor told my husband and then he told me. I cried for two whole days. I cried for the disappointment of my other children and out of fear. After all, we were not getting any younger. Then we brought him home and my mother died and my husband came down with a suspected tumour in the lung. We thought he had cancer. This was the worst time in my life. The neighbours came in and told me I would be better off without this child and I had to ask one neighbour to please leave my home. One neighbour said, "He looks like a little old Chinaman". Miraculously, my husband got better. The tumour disappeared. He got a clean bill of health. More and more, Brian began to change our lives. He was very sickly you know, and he had a very large tongue which used to choke him. When Brian was two, we became members of the Down's Syndrome Association which issues Newsletters now and again. There was an article in one of the Newsletters by Professor Browne who said that all Down's Syndrome sufferers who had long tongues should have an operation to shorten them, thereby allowing them to swallow more easily. Brian had this operation August last. We think he is the first one in Ireland, and certainly he is the first one in Kerry, to have this operation, and he is now eating solid

food. The children adore him and we are all so proud of him. We know he is an intelligent child. You can't imagine how affectionate he is and all we want now for him is that he will be able to reach his full potential. He is included in all our activities and he knows he is the centre of attraction. We want the best for all our children and we hope to make Brian as independent as possible and we have great hope for the future as we know that new discoveries are being made all the time in this area."

CASE NO. 63

Nora Casey is 55 and her daughter, Mairead, who is handicapped, is 15. She lives with her husband and two other children, 19 and 17.

"When Mairead was born, I was suspicious from the very beginning that something was wrong. Nobody told me. I was told by the doctor to come back in a few weeks with Mairead and he passed this off by saying, "They take more care of babies than of the mother now". Still, that feeling was there. She was only a few weeks when she got very sick. She had a chest problem. I thought she was going to die. In fact, on our way to the hospital, my husband and I were discussing where we were going to bury her. When our local doctor looked at her on arrival, I heard him say, "My God, what can I do with her?" He held her up to the light and looked at her very closely. He had got his information already, of course, but he never said anything to me. I was called to the clinic then and the bottom fell out of my world. I felt I was in a dark tunnel with no light at the end. Michael couldn't go to Tralee with me that day and I had to take the blow all on my own. My daughter was handicapped. She wasn't very old when I got hepatitis myself and had to spend three months in Bantry Hospital. It was a combination of hepatitis and depression caused by the fact of Mairead's handicap. There were terrible days there. Somedays, perhaps, I wouldn't have any visitors as it was very far from home. It was so lonely and depressing. But I think what kept me going was reading. Mairead was at home for part of the time. My mother-in-law looked after her. She was in hospital a great deal too and you might say that the nurses in Kenmare Hospital reared her for the first few months. One good thing about my stay in Bantry Hospital was that it opened my eyes. There was one nurse there who was very good and who used to talk to me a great deal about handicapped children.

All of this talking helped me greatly and I felt better. We got on fine then though she was still being bottle fed at the age of three. I didn't have the time or the patience to encourage her to spoon feed. At three, she got a very bad attack of chestiness and we had to go to St. Finbarr's Hospital, Cork. I thought she would die again this time. My husband's sister was a nurse in St. Finbarr's at this time and this helped us greatly. We were so grateful that Mairead got well again after this bout. My sister-in-law in Cork and the local curate here and a few other relations got together and persuaded us that she would be better off at Beaufort. My local parish priest, on the other hand, was against this idea. That put pressure on us. But what really convinced me was her illness. I felt she would be better looked after if she were somewhere where she could have ready access to a doctor. In the beginning, I found it very hard. We used to visit her in Beaufort every three weeks and every time, I just cried and cried. One evening I didn't cry and I mentioned this to one of the nurses, that I mustn't be a good mother to leave my child without crying. She said, "Why should you cry?" I realised she was right. Crying wasn't going to help the situation at all.

All that hassle has passed now. She comes and goes in the bus every week-end. Though, mind you, I find that if we bring her back ourselves to Beaufort, we all get upset again. Otherwise, she is getting on very well there. In the beginning, I felt bad about sending Mairead to Beaufort. I felt that God had sent her to me and that I was letting God down by not caring for her myself. Now I am happy because I feel she has got every chance. Her speech is not wonderful, but at least now I know she has one of the best speech therapists available, so I have no guilt. I am convinced it is harder to leave them go than to keep them at home. When you keep a child at home, you have peace of mind. They are under your eye and you know what's happening. But when you send them away, while you know you are giving them a great chance, you worry in case they will be lonely or sick. I have adjusted a good deal to all that now. I cried, too, when I saw Agnes, her sister, going out dancing. I knew Mairead could never go with her to dances. I am over that hurdle now too. Now, I am more worried about Agnes with the way the world is going. At least, Mairead will always be protected."

CASE NO. 64

James Kerrisk is 62. He is a bus driver and he has a son and a daughter, 17 and 13. He is a widower. He looks after his daughter, Dolores, who is 18.

*"When my wife died eleven years ago, I took on the responsibility of looking after Dolores when she came home every week-end. I look forward to her coming now as she is no trouble and can be better than the other two sometimes. She was about twelve months old when we found out she was handicapped. We kept her at home until she was five and then she went to Beaufort. She got great training there and can do anything around the house."*

CASE NO. 65

Joan O'Sullivan is 46. She is married with one daughter, Majella.

*"When I found that Majella was handicapped, I experienced a great trauma, a frightening experience. I had no one to turn to in the beginning. My husband was very much afraid of the situation too. I cried a lot in those early days. In the hospital where Majella was born, I got great support from a nun who had a brother who was handicapped. On coming home, I did not go outside the door for three weeks. I felt a sense of shame in front of the neighbours. Then Christmas was coming and I had to go out. In the beginning a friend asked me if I would have preferred if Majella had died at birth and I answered that I would. But as time passed and I began to grow to accept the situation more, I became delighted with Majella. In the beginning, the district nurse was very helpful to me too. At present, I find the situation as normal. I live a normal life and so does Majella. She lives as normally as she can, given the situation. She rises in the morning, attends the school at Beaufort, going back and forth by bus, comes home and spends the evening with the family."*

CASE NO. 66

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Noreen O'Sullivan is 39 years of age. She is married with two boys, aged 5 years and 1 year. Her daughter, Breda, is the handicapped child and is 8 years of age.

*"She was four days old when the doctor told me Breda was Down's Syndrome. I lost my head and screamed and shouted. I have never really come to grips with it over the eight years. I never can, deep down. She was easy to rear, a great sleeper. She was slow to sit up and walk though. At a year and eight months, she walked. My husband accepted it much better than I did. She is not a difficult child. She is bright and is doing well at school, but I can't get rid of that terrible feeling about her being handicapped. I don't think I will ever get over it, even though she is not badly handicapped."*

CASE NO. 67

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Elizabeth Gentleman is 57 years of age. She has five children, the youngest of whom is 14. Her handicapped daughter, Anne Marie, is 12.

*"When Ann Marie was born, she was twelve pounds and very purple and puffed. The nurse delivered her in St. Anne's, Tralee, and they told me she wasn't well. I could see that for myself, that she was handicapped. I was shocked. I told the doctor to take her away. I didn't want her and, strange to say, to-day, I wouldn't part with her for the world and the boys are mad about her. What an awful shock for any woman. You could walk yourself to the sea and throw yourself in at that moment. But now when I see even young girls having handicapped babies, it's difficult to understand. But I find the meetings of the parents very good. You will always see cases that are worse than your own."*

CASE NO. 68

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Maura Keane is 41. Her husband works with the Department of Agriculture. She has four children aged 15 to 9 and a daughter, Niamh, is 13.

*"I was suspicious from the start that there was something wrong with Niamh. When she was three*

months we took her to a doctor and he said she was fine. When she was four months, we took her to The Children's Hospital, Harcourt Street in Dublin. They did tests on her and said they thought she was spastic. When she was ten months old, it was confirmed that she was severely handicapped. It was terrible being told this final diagnosis. Then we took her to the Spastic Clinic in Cork for physiotherapy every week but that didn't do her very much good. When she was one year and nine months old, we took her to America, to the Institute for the Achievement of Human Potential, Doman Delacata, and we worked on that programme for two years with re-assessment every three months. She improved a lot on that programme and it also gave us a better understanding of her. It was during that programme that she became a person for me and from then on, she was treated as another member of the family. She is completely immobile and everything has to be done for her but she is very happy and very quiet. My only problem is if I don't outlive Niamh, what is going to happen to her. At this time, in this area, the only place for mentally handicapped children with her degree of disability is the Psychiatric Home in Killarney. This, of course, would be terrible to contemplate."

#### CASE NO. 69

Kathleen Hickey is 43. She is married and has three children. An uncle-in-law lives with them in the house as well. Her handicapped daughter, Michelle, is 7 years of age.

"Six weeks after she was born, I was told that Michelle was mentally handicapped. Her birth was very slow and complicated. I was very upset when I heard she was handicapped and cried and cried for days. I had a mental breakdown at that time, but I had to accept the situation and we decided that we would do everything we could for her. The public health nurse called a lot to me and was a great support. Then I got in touch with other mothers and it was consoling that some of these had worse cases than mine. Thank God, she can walk, can understand some things. But she was very troublesome when she was growing up and she would throw toys at the television or at the window. She was also very bold but a lot of this has worn off. She often locked herself into the bathroom and we had to break down the door. But, thank God, she is much better now. It's grand to get the break when she's at school."

CASE NO. 70

Mary Wall is 30 years of age. She is married with three children, aged from 9 to 1 and she looks after her husband's brother, Frank, who is 23 years of age.

"Three years and three months ago, I started looking after Frank when his father died. His mother had died sometime before and the father had looked after him for those years. But then when the father died, not one of the other members of the family were willing to take him into their own homes. We are glad to have him and it's a good thing for our own children too, I think, that he is here. Frank was a resident at St. Mary of the Angels in Beaufort for ten years before his parents took him out to live with them. They didn't have a bathroom so his father used to bring Frank to our house for a bath every week. Then when the father died and the other members, and there are ten of them, all refused to have Frank, we felt that we ought to take him. He is no trouble really except for the things which I have to do for him. I am English myself and met my husband there and we moved home some years ago to live here."

CASE NO. 71

Phil Moriarty is 58 years of age. She lives with her husband and her son, Fergus, 23, who is handicapped.

"Fergus was about two years old before I noticed there was anything wrong. I remember saying to my mother that he was very slow. Eventually, I took him to a specialist who told me that he was retarded. The bottom fell out of my world. It was an awful shock for me and more especially for my husband. But what could we do, only accept it. He was the only one we had. He brings us great joy now even though he is handicapped and we love him very much. I suppose it would be worse if we had no child. I am delighted with his present job in the Workshop and I thank God for the St. John of God Workshop in Tralee."

CASE NO. 72

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Marie Daly is 37 and lives with her husband and daughter who is 8 and her handicapped son, Michael, who is 10.

"When Michael was born he was in an incubator and was very sick. He had to be fed through a tube. He was in St. Finbarr's Hospital in Cork for a few weeks. They told me there that he would be a slow learner. They wanted to keep him and send him to a Home in Cork, but we couldn't leave him. We would die without him. So we brought him home and he was fine. When he started to walk at about one year and ten months, we noticed that he was dragging one leg pretty badly. The doctor told me that he had weak muscles in his thigh. I started bringing him into Tralee and he goes there regularly for physiotherapy. I do the therapy at home myself as well twice every day. We have to straighten the leg and lift it to see if we can strengthen the muscles. He has to call to see a specialist on the 2nd December in Tralee and I hope that they'll do something for him. I'd like it if they did fix his leg before he gets too much older. He went to the local national school for a year but didn't make much progress. The teacher hasn't much time to give him the special attention that he needs. I'd prefer if he could go to the Special School in Tralee. I think he's too good for the Beaufort school and he's picking up a lot of bad habits from the other children there. They told me in Beaufort that he'd find it too difficult in Tralee just now and to give him another year in Beaufort. He has a great friendly way with him and if anyone comes in he has his hand out to welcome them and invites them to come in. I have great pity for him and I worry about him. But what can a person do? I'd never leave him into a Home and we'll do the best we can for him here."

CASE NO. 73

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Ann Kelly is 59. She lives with her husband and she has fourteen children, all older than her son, Joseph, who is the handicapped child.

"I blame myself really. I had enough children, thirteen before Joseph. I should have been satisfied. I'll never forget it when he was born in Caherciveen Hospital. All I kept hearing was, "he won't live", "he won't walk",

"he will always be sickly". He was brought up to Tralee for tests. I was called up there by a specialist. It is a forty miles journey. What did he tell me? "He won't live, he won't walk, he won't talk". So I told him if he had nothing new to tell me, he could have spared me the forty mile journey. Then Joseph was taken to the Regional Hospital, Limerick for a while. After six weeks or so, I got word to bring him home from there. I'll never forget the state the child was in when I collected him. The first thing I noticed was that he had diarrhoea and they had no nappy on him. I remember I had a white cardigan on me and I used that as a nappy for him. It was a disgrace. I took him home that time and I swore he'd never go to hospital again. He was very sickly from then on and often got croup. I tried to cope as best I could myself and only called the doctor as a last resort. My twins were only two at that stage, so I suppose I was kept going. Of course, my older daughters were at home at that stage and they helped. My oldest girl took a great interest in him. When he stopped being sickly and began to get strong, I realised that Joseph was going to live irrespective of what the doctors told me. When he was about six, I heard about Beaufort and was advised by people to send him there. I did so. He gets on very well there and comes home every week-end and comes home for his holidays at Christmas, Easter and Summer. We are all very fond of Joe and I suppose I spoil him really. I do sometimes have a feeling of being tied down by Joseph when he's at home, but he's a lovely little boy and I don't mind."

CASE NO. 74

Eileen O'Sullivan is 60. She is married and has her husband and her sister living with her and a son who comes during holiday time. Her son, Patrick, is handicapped. He is 14 years of age.

"I have to say that I have come to terms with it at this stage. I was very disappointed at first and very puzzled. Everyone else knew before I knew. He was born in Caherciveen Hospital and a lady in Caherciveen town told me afterwards that she knew the morning he was born that he was a 'Mongol'. That hurt me deeply. Mind you, something did strike me about his eyes very shortly after he was born but I put it out of my mind again. It was the local district nurse who dropped the bombshell. She came regularly after I brought

him home from hospital. She used to always come at the wrong time, when the lads were coming home from school and I would be up in a heap. I was wondering why she should be coming so often. Then she told me he was Down's Syndrome. She didn't explain anything about the condition to me but gave me examples of other children in the locality, one who attacked his parents and one who went around peeping in windows at night. I was left with the impression that I had a sex maniac or somebody very dangerous on my hands. I was frightened and puzzled. She advised me to put him away. I was in a terrible state. Do you know I had to force myself to feed him when he cried. My husband lost weight and I myself lost a great deal of weight too. But by degrees I met people who explained what Down's Syndrome was. My sister is a nun with the same Order which run the Home in Beaufort. So I went up there and they encouraged me to apply for a place. I put down his name. In the meantime, I was working away with him at home. He walked at one year and ten months. I got him toilet trained at an early age too. Then I sent him to the local national school, but there were a lot of young children in Baby Infants and the teacher hadn't time to give him sufficient attention so Patrick began to soil his pants, something he had never done before. I then decided to send him to the residential home in Beaufort but I brought him home every week-end as it broke my heart to leave him behind me there. My husband didn't want him to leave the house at all. He told me that I could teach him as much as they could there. I'm sure I could too, but as the nuns pointed out when I used to bring him up there on a daily basis initially for speech therapy and so on, it's in the child's social development that the residential school scores. I found it very hard to part with him in the beginning. I'm used to it now though. He's great now and, as I've said, I've come to terms with it. He can cycle. Yesterday, for the first time, he put a sentence together. That gives me great satisfaction."

CASE NO. 75

Mary Brosnan is 46. Her husband is a farmer and she has ten children, 19 to 6. Bernard is the handicapped one and he is 6.

"Looking back, the one thing I noticed when I was expecting Bernard was that I was very dizzy in the mornings. Otherwise I was in the best of health. He was born in Killarney and he was the

only baby in the hospital at the time. The nurse told me never cried when he was born and he wasn't taking his bottle from them. Then the doctor told me he had jaundice and they were sending him to Cork for tests. He was there for six weeks. I have a sister a nun in the Cork Regional Hospital and she used to phone me and tell me how he was. I was to bring him home for Christmas then one of the sisters found he had a hole in his heart, so he had to go on special medication at this stage. I was getting suspicious and when I went to collect him in January they told me he was Down's Syndrome with complications of the heart and they didn't know how long he would live. There and then I decided to do the best I could for him. My mother-in-law had been in the house with us and she had just died and it seemed to me that this child had been given in her place almost. It seemed that I was destined to be caring for someone. He is six now and is off all the medication and I had him in Cork recently and they told me that I needn't bring him back for two years and that seems to me to be a good sign. I would love now to have him at school. He is six and I feel he would be better off with strangers his own age. His father however doesn't want to part with him and has refused to do so up to now. But now that he is six, I think that it would be good for him."

#### CASE NO. 76

Mary Dee is 42 and she has two daughters, 16 and 15, and her mother who is 75 years of age as well as Patricia, her handicapped child, who is 18.

"Patricia was born in England and at nine months I realised that she wasn't sitting up and doing the things other children at her age were doing. I took her to a specialist and he didn't accept that she was handicapped as she looked quite normal and was putting on weight. She was born six weeks prematurely and only weighed 3 lbs. 2½ ozs. and was in an incubator for eleven weeks. She was 5 lbs. 2 ozs. when I took her home from hospital. On my own instinct, I took her to another specialist and had tests done and it was confirmed that she had Cerebral Palsy and I was told she would never walk or never talk. It was an awful shock to me when it was confirmed that she was handicapped, even though I had suspicions that something was wrong with her. My husband was great support and only for his help I couldn't have got through. Gradually, we began to accept it and got used to it. It meant a lot

of time was spent in hospitals, taking her for speech therapy, for physiotherapy and a lot of time involved each day in doing exercises with her. It meant getting up a couple of times each night to turn her in the bed. She got convulsions also and this meant that I couldn't leave her with anyone else, so I was looking after her twenty four hours every day. We didn't have any social life when she was small. When she was four years she went to a handicapped school in England, being collected and brought back each day. That was a great break for me as I was free to go shopping and so on during the day-time. She was six and a half years old when we came back to Ireland. I was unable to get her into a non-residential school here and then we heard of a five-day school in Lota in Cork but it didn't suit her. So I took her back out of there. She got a kidney infection there. She stayed three months there. Then she went to a Special School in Limerick, St. Gabriel's, where we collected her and brought her back each day. That school became a national school so she was at home for a while and then we got her going to the Lixnaw school. She was there for six years until she was 18 years recently and now we are hoping she will be placed in the Workshop for the handicapped. There have been some very difficult times. Even last October, I thought I was going to crack up."

#### CASE NO. 77

Eileen O'Donoghue is 56 and her husband is a shop-keeper and she has five children aged 26 to 18. Danny, her handicapped boy, is 22.

"Danny was born in Chicago. Children are not allowed to go to school in Chicago until they are five. We left Chicago to come home and live in Ireland when Danny was just that age, with the result that he was well over five when he first went to school here. I think that is what happened to him. He was in with children younger than him and he was frustrated. I don't like the term handicapped at all. Danny is not handicapped, he is slow. He did his Group Cert. you know. I had him assessed in Lota and they told me he needed remedial teaching because he was slow. Danny is very sharp and he is better off with strangers. He did an AnCo course and they put him into the St. John of God workshop and that was the worst thing that could happen to him. They were much worse than him, you know. He didn't fit in. Danny is a borderline case. He is neither fish nor flesh. WadCo took him in some time ago. He was in the

stock-room, but they started to leave people off and Danny had to go. There would have been a strike if Danny had been kept on, but he has References from WadCo and good ones. If only someone would give Danny a break. He won't get up for his father in the mornings, but he will get up no bother next week when he will be going to Kilkenny. Danny would be a good worker if only someone would take him on. He was with the Killarney Advertiser newspaper but, when his six months were up, they took someone else on. He was very disappointed. I don't know where he gets his dirty language from and he can be very stubborn. His father worries a lot about him."

CASE NO. 78

Mary Mangan is 55. She is widowed. She has two children, 23 and 18, with her and her mother, 88. Her son, John, is 25 and is the handicapped one.

"I was very small when I was carrying John. The doctor questioned me if I had my dates right. I already had a still-birth. It was two weeks overdue. So my doctor wouldn't take any chance this time. He took me into hospital. I got various injections and labour was induced and John was born. He was 4½ lbs. He was very bad for eating and they fed him through a tube. Then they decided that they'd keep him a while longer and train him to a bottle. I used to visit him every time I went to Killarney shopping. On one such occasion in Killarney, I met one of the nurses. She was as good as any doctor and she told me that he had greatly improved and that he'd raise his little head when he'd see me. He did just that, and do you know, I thought I saw something in his eyes that day. But, of course, I wouldn't believe it. If anything was wrong with John, wouldn't the doctors and nurses have told me, I thought. He came home after a few weeks. At night, after the others would go to bed, my husband and myself would sit by the fire and we'd be looking at John. Both of us felt that something was wrong but neither of us wanted to be the first to say it. When he was nine months old, I took him for his first injections. I was told then that he would be slow, that what normal children could do in three months, John mightn't do for twelve months. Down's Syndrome was mentioned. I couldn't bear it. I cried and cried that day. We taught him to walk along by the chairs. We repeated simple words for him and he'd say them after us but he'd never say them off his own bat. We persevered with the toilet

training and eventually we succeeded. There was never any question of sending him anywhere because the doctor had mentioned the first day he told me about John's handicap that he'd be better off in an institution and I had shuddered. It sent shivers through me. Then there was a Mission and the priest visited our house. He told us to make up our minds and send John to where he would have some schooling, otherwise, we'd be doing the child an injustice. We didn't want that at all and we took the priest's advice. We wrote to a number of places. Beaufort was only starting up then. We went over there and the Matron told us that they could not take him for the moment but that when the place got under way he would be the first boy admitted. Then we got a call from St. Michael's House, Dublin. I'll never forget that train journey up. We were miserable. The first sight we saw when we got there didn't cheer us up at all - old men sitting in chairs in the grounds shaking themselves and nodding their heads. Then the Matron was stiff out too. She told us the best thing to do was to leave him there and go home. I'll always remember that picture of him at the top of the stairs. He looked to helpless and so sad. We rang every week to see how he was getting on. They would say he was fine. At Christmas we guessed that all was not well. He came home the following Easter and still didn't want to go back. He didn't like it there and we were upset because of that. He spent another year there however. He had to. There was no place else. Then word came from Beaufort that they had a place for him and we were very glad. He was almost finished his term in Dublin so the sister in charge in Beaufort advised us to allow him to finish his term there and then to bring him along. When we took him there we used to see mothers and fathers crying when they left their children there. We couldn't understand them at all. We were so happy to have John accepted there, we had gone through so much in Dublin. When he finished his time in Beaufort, he went to St. John of God's Workshop in Tralee. He found it strange in there at first because he stayed five nights, coming home at the week-ends. But he was happy that some of his former friends in Beaufort were now working there with him. So we got in touch with the Kerry Parents and Friends regarding the possibility of getting him a place in the Killarney Workshop. We were delighted when the phone call came to tell us that he could come. All the family discussed it before hand. Before we decided, we considered the full implications of what it would mean to have him at home here all the time. We came to the conclusion that since he was here three nights a week as it was, the extra four nights would make no difference. It's

easier that way. When he was going away for the week, he needed a case of stuff going. Now, it's like any other child going off to school and coming home each evening. He's delighted that he can come home every night to his own bed. He does his own little jobs around the house and he helps with looking after my mother. He's no trouble at all. I suppose really I'm more tied down with my mother than I am with John, as she is 88. I am lucky though that all my family are around me. My daughter is next door. I mind her children if she wants to go out and she comes here to look after John and look after my mother when I want her to. I suppose to me John is like having a young child around the house all the time. John is just different. He needs a little extra care. My mother needs much more care since she is 88 and I have to do most things for her, but there is no question of putting her into a Home. I'm an only daughter and my mother and myself have always been very close."

CASE NO. 79

Maura Murphy is 49. She is a primary school teacher. She has five children. Her husband is a butcher. Her daughter, Orla, is 10 and she is the cared-for person.

"I never got over the shock of having a mentally retarded child. Looking back now, I can honestly say that it wasn't so much the shock of having her. It was more the way I was told. The paediatrician threw it at me. That is how I can only describe it. He said, "Your child is a mongol and what can you expect at your age". I think I fainted at that stage. However, there was a nun there who was very kind to me and I regretted that she didn't get a chance of breaking the news to me. I was 39 when she was born. Most mothers have a fear of having a handicapped child, but I must confess that the thought never entered my head. I already had four daughters and I had given birth to each of them without any trouble. So I had no reason to believe that this would be an different. Before she was born I used to play a lot of Bridge and I was anxious to have the baby so that I could get back to Bridge and to my friends again. That was ten years ago and I haven't been able to play Bridge since. I was left out of hospital after three days and they kept the baby two weeks for me. I told them I didn't want to bring her home, that they could do what they liked with her. At that stage if a tinker going the road wanted her, I'd have

given her away. The nun at the hospital told me not to leave her at the hospital too long because it was vital to form a bond quickly. I brought her home after two weeks and for twelve months I didn't have any feeling for her at all. When she was around a year old, I was going to Cork one morning and Orla was sick. I phoned the doctor and left the housekeeper in charge and went off. I would never have done that with one of the others. When I came home, she was in hospital and was critical with pneumonia. The doctor was very annoyed at the fact that I had gone off to Cork without a second thought. I spent the night with her in the hospital and prayed that night that if she got well, I would make the best of things and would be a better mother to her. I haven't looked back since that night. Believe it or not, I am a better person because of Orla, less interested in material things and Orla has turned out to be the most loveable and kind of all my children."

CASE NO. 80

Molly O'Shea is 71. She is a widow and her only child, James Noel, is 31.

"Jimmy was born in St. Catherine's Hospital, Tralee. My first child was still-born and I had two miscarriages after that so Jimmy was my last and only surviving child. My husband and I were delighted. We thought he was perfect and it wasn't until he was two years old that the local doctor told me that he was retarded. As a baby he was constantly sick. I think I had the doctor with him for every tooth and when he was six months old he came down with pneumonia. I thought he was finished that time. I had so many ups and downs with him that I was just glad he was alive. That is how I felt. I think I must have accepted it straight away when the doctor told me he was retarded, but his father didn't. He was both disappointed and worried. He worried over what would become of Jimmy in the beginning and thought it would be better to put him into a Home. I wouldn't hear of it. Jimmy was mine, sent to me from God, and if it was to be my Cross, I would carry it as best I could. So I kept him and reared him with gentleness. The more gentle you are with these children the better they will become as they thrive on praise. I am well rewarded for it. He stayed at home until he was 27 as there was no way of sending him to a school and he was with me

at all times during those years. Then when the Adult Workshop opened in Killarney they persuaded me to let him go there and he goes there now every day to the Workshop and comes home each evening. They had a Hallowe'en party there and they got apples and nuts and each of them got a packet of wine gums, and he came home that night and took the packet of wine gums out of his pocket unopened and handed them to me. It gave him more happiness to give them to me than to eat them himself. When I was a young girl at the age of twelve preparing for my Confirmation, in our Catechism there was a phrase which I never forgot: "Shall the mother forget the child of her womb?"

CASE NO. 81

Mary Fleming is 36. Her husband is a farmer and she has five children altogether including Johnny who is 11.

"Having a handicapped child is a terrible misfortune. It was worse that he was the eldest. If he came third or fourth in the family it would have been better, for Patrick would have been a great help with him. Patrick is a great little boy and helps me with the other small ones. He was up every morning during the holidays at 7.30 milking the cows. He says, "Mom, you did them long enough, I'll do them now". Patrick is only ten. Indeed, Patrick always felt neglected because of Johnny. "Why don't you feed Johnny?", he'd say or he'd say, "Johnny can get away with anything". Johnny, our handicapped child, brought us bad luck. We buried two children when they were two years old. Johnny was four, Patrick three, Martina two and they were sitting by the fire. I was milking the cows. We had a fire guard around the fire, and to this day, Patrick says Johnny took off the fire guard. Martina's clothes caught fire and she suffocated. Then the following year, Kevin, then two, went to the creamery with his father on the tractor. The tractor door opened and Kevin fell out and was killed. That was the end and to have a handicapped child on top of all that. That was a terrible time and I don't know how we came through it. We sold off our cows and moved out to my own people's place near Listowel. My husband blamed himself for Kevin's death. He stayed in bed all day. He wouldn't do anything. Poor Patrick had an awful time from me at that time. He'd ask why we were crying, why was daddy in bed all the time, where were Martina and Kevin gone. He drove me mad. I used to shout at him and slap him. It was awful. It hurt for a long time to talk

about Heaven and that Martina and Kevin were gone there. It's only now we can do so painlessly. Anyhow, we had no livelihood in Listowel, so we came back here again.

The funny thing was we never realised Johnny was handicapped until he was three. You don't realise with the first one. I used to bring him into the doctor in Killarney complaining that he was slow at walking but he'd only say, "He'll walk soon enough, he'll be into everything then". At three he still wasn't making much progress and the doctor made an appointment to have him assessed in Cork. I couldn't believe it when they told me he was handicapped. I cried bitterly. He was very cross, awful in those early days. He'd throw things through the window, throw things at the younger ones. I had an awful time. As I say, if he had come later in the family, it wouldn't have been so bad. Cecilia, the social worker from Beaufort, came and shortly after, we got a place in Beaufort. My husband didn't want to send him to Beaufort at all. He said I could mind him here myself. But that was ridiculous. He was coming home then every night for a while, but I couldn't cope with that anymore. The people are still anxious that I would take him home every night but there's no way I could do it until the young ones are bigger though they are mad about Johnny and love to see him coming home. They don't realise the responsibility which caring for Johnny means. Then too I think he has a kind of bad influence on them. If you ask him to do something, he says, "No", or to go to bed and the answer is, "No". He also picked up a lot of other habits in Beaufort which I wouldn't like the other children to pick up. You see, the good and the bad are mixed up there. I don't blame them. They haven't the facilities to do otherwise. He was at home during the holidays and he comes home at week-ends and that's about as much as I can do at the moment. Of course, I suppose if the people in Beaufort said I'd have to take him home every night, then I would get used to it again. I don't go anywhere while he's at home because I'm afraid he'd create a scene. On the few occasions that he did go, my husband gave out on the way home about Johnny's behaviour. So it came to the point where I make an excuse and stay at home with them. It creates hassle between my husband and myself. He makes me mad. He's always asking where Johnny's handicap comes from, that it must have been from my side of the family. Well, no. No one on my side was ever handicapped and I tell him that, and anyway, I tell him that it doesn't matter, he's here and we have to take care of him, or rather I have to take care of him. He's always on about it."

CASE NO. 82

Susan O'Sullivan is 55. She lives with her husband and three children, 18 to 13 and her daughter, Anne, is 11 and is the cared-for person here.

"I hope you won't be disillusioned with me. I didn't want this pregnancy. I had no love for the child I was carrying. I have said to numerous priests that men should be lectured on their responsibilities, but I haven't heard it yet. At my age, I did not want another baby. I had four other small children, but that was it. My old mother-in-law of 92 was here in the house too at that time. She was incontinent and had to be hauled in and out of bed. I had to go to hospital, to the Erinville in Cork, for a rest in the eighth month of my pregnancy. While there, the consultant did some tests on me, but they wouldn't tell me why. Then he announced that labour would be induced, though I was only eight months. When she was born I asked about her. When the sister-tutor told me she was physically and mentally retarded I was shattered. I had been struck at my weakest spot. I was dumb-founded. I was very angry and lashed out at the doctors and the nurses and at anybody else within earshot. I blamed them for causing her handicap by the induction of labour. She wouldn't feed and you couldn't hold her. Her arms and legs just flapped about. How was I going to face home to four young children, to a bed-ridden incontinent mother-in-law and to a house without water or sanitation of any kind? It will tell you how bad it was. I used have to wash the sheets from my mother-in-law's bed in a stream near the house swilling them up and down in the water. Before I was due to be discharged, I explained this to the sister-tutor and pointed out to her what a bad feeder Annie was and so on and the hospital agreed to keep her and they did so for six weeks. It was awful then. I don't know how I survived those years, but I did. I am as tough as nails now. Nothing would move me. I have lost hope and interest in everything. There was no support. Michael, the next youngest, was a year and a half when Annie arrived. I used to have to strap him into his chair while I was feeding her. The feed could take up to two hours. He was neglected, the poor child, and shows the effects of it to-day. He's very difficult, a real problem. I took him to the doctor to have him psychoanalysed, but the doctor said my husband should be psychoanalysed and not the child. You see, my husband gives Michael no chance. Last year, he gave him a calf. However when it came to the time to sell the calf, my husband kept the money,

so Michael steals it from his pockets - he feels he is only taking his own money. Then he gives no example. As you can see from the state of the place, my husband is a ne'er-do-well so the child is reacting to his environment. He picks on Annie, teasing her, pulling her hair, and this makes me very mad. Those first years Annie reminded me of a dead rabbit. You'd hold her in your arms and her legs and arms would just flop around the place. It was very hard to feed her. I felt isolated. The first time the district nurse came, do you know what she said to me? "Well, what can you expect, having intercourse at your age?" As if I wanted to have intercourse. So we didn't hit it off very well that day. Then on her next visit she said, "There's no improvement here at all", when she looked at Annie. I was very hurt at that because I thought there was great progress. My sister knew the sister in charge in Beaufort and when Annie was only a few weeks old, she brought me to visit her. She offered to take in Annie at that stage, but I said I'd have a go at home first. I was able to keep going because her offer acted as a kind of prop to me, and wasn't she changed to Africa, that same nun, and that was the end of that. The local doctor in Kenmare was good too, and on a few occasions when she saw I couldn't cope with Annie, took her into Kenmare Hospital for me. About four or five years ago, the social worker from Beaufort called around and gave me great hope that Annie could find a place in Beaufort. She went there when she was seven. It struck me at my weakest point when Annie was born. I had a horror of handicapped children always. When I was nursing, I couldn't understand the attitude of mothers who wouldn't be very enthusiastic about their handicapped child. A friend who worked with me had a handicapped child. I felt it was a judgement on her that this baby should be born and I never went to see her and now here was I myself with Annie, but I have got over that now, mostly anyhow. I feel I should be doing a lot more for Annie, but there's no money here for the extra amenities for Annie. My husband never gives me money. I have the same coat for twenty years. My sandals I bought after Annie was born with the last of my own money. But I often say to the other children in the family, "I wonly wish ye were as little trouble as Annie". She more than repays any love I give her and is a great consolation. She comes home for week-ends now and for the holidays three times a year. The district nurse called recently to see if I would bring Annie to Lourdes. I told her however that I didn't want any miracle to cure Annie. She wouldn't be my Annie at all then. But if I was a deeply religious person, I would probably consider the whole thing as a guarantee

*of sainthood. The experience has taught me that nothing is hopeless - where you'll least expect a return, that's where you'll find it. Annie is my biggest consolation now, whereas in the beginning she caused me so much trouble and worry."*

CASE NO. 83

Helen Corkery is 27 and her husband is a Post Office employee. She has two children, John, who is 1 and, Elaine, who is 2½. Strictly speaking, Elaine does not belong to this study at all, but she was on the waiting list for St. Mary of the Angels, Beaufort, and it was assumed that she was moderately handicapped. It turned out that she suffered from a brittle bones condition. Nevertheless, I think that her case is worth reporting.

*"From the moment of birth, I knew that there was something wrong with Elaine. The nurse and doctor mentioned that her legs were bow-shaped and I was suspicious straight away. It was an extremely difficult birth. She was born with multiple fractures and my first reaction was to blame the difficult birth for this, but subsequent X-Rays showed that she had incurred many fractures and breaks while she was still in the womb and these had knitted. The doctors told me that she had a condition known as brittle bones but that's where the information ended. She was born in the Erinville in Cork and the professor said he recalled a similiar case in the hospital a few years ago, but as there had been no follow-up on it, he could not give any names. I brought her home and for the first six months I suffered depression and frustration because I could not find a doctor who knew anything about the disease. I felt that I should be giving her some form of treatment to strengthen her bones. If she was handled roughly at all, she could sustain a fracture. It was possible to break her leg by just changing her nappy. She is 2½ now and is crawling everywhere; when she tries to stand, she breaks her leg. Her little brother, John, is only 1, but I have to try to keep them apart as he is rough with her. Do you know what is the worst of it all? If she gets a break or a fracture, she goes into shock and she cries and shakes all over for a couple of hours until she falls asleep from sheer exhaustion and the doctor won't give me any pain killers for her. That is very traumatic for myself and her father and for Elaine herself naturally. About six months ago, I heard of an*

association in Scotland called "The Brittle Bones Association" and we became members. My husband, Dermot, and myself went to Dublin recently to meet with parents that the Association put us in touch with, and at last, it is great to have someone to discuss our fears with. The medical profession are still no help to us. They know absolutely nothing about the disease. Unfortunately, Elaine's teeth are affected. They are breaking and discolouring. We are just keeping our fingers crossed that she won't have progressive deafness as the Association told us that this can happen in some cases when there is softening of the three inner bones of the ear."

APPENDIX 2

QUESTIONNAIRE FOR CHIEF CARING PERSONS OF  
FRAIL ELDERLY AND HANDICAPPED CHILDREN

*(Instructions for interviewer are in italics and in brackets)*

A. GENERAL DATA:

1. Name of Principal Caring Person (carer): \_\_\_\_\_

2. Address: \_\_\_\_\_

3. Age of carer: \_\_\_\_\_

4. Sex of carer: Male 1 Female 2 *(Ring appropriate number)*

5. Although we have agreed that you are the Principal carer, is there anyone whom you would consider to be almost on an equal footing with you?

Yes 1 No 2

6. If YES, please state who it is: \_\_\_\_\_

7. Occupation of carer: \_\_\_\_\_

State whether - Fulltime 1 Part-time 2

8. Has carer others who are dependent on him/her?

Yes 1 No 2

9. If YES, list them fully: \_\_\_\_\_

10. Does carer live in same house with cared-for person?

Yes 1 At night only 3

No 2 During daytime only 4

11. If living in same house, who else lives in the house? \_\_\_\_\_

12. Marital status of carer:

Married 1 Widowed 3

Single 2 Separated 4

13. Cared-for person:

Frail old person 1 Mentally handicapped 2

14. Name of cared-for person: \_\_\_\_\_

*(Note: Use cared-for Person's Christian name from here on.)*

15. Age of cared-for person: \_\_\_\_\_
16. Sex of cared-for person:    Male    1        Female    2
17. Relationship to carer: \_\_\_\_\_
18. Marital Status of cared-for person:
- Married 1                      Widowed    2
- Single    3                      Separated 4
19. Previous occupation of cared-for person \_\_\_\_\_
20. Who else lives in household with cared-for person? \_\_\_\_\_
- 
21. Do any relatives of cared-for person live closely (within 1 mile)?
- Yes        1                      No            2
22. If YES, who are these relatives?
- Son    (....)    Daughter (....)    Brother (....)    Sister (....)
- Niece (....)    Nephew (....)    Ist Cousin (....)
- Parent (....)    Other (....) - Specify \_\_\_\_\_
23. Do any relatives of carer's who are not related to cared-for person live closely (within 1 mile)?
- Yes        1                      No            2
24. Any such relatives of carer or cared-for person live within the following distances?
- |                  | CARER |   | CARED-FOR PERSON |   |     |   |    |   |
|------------------|-------|---|------------------|---|-----|---|----|---|
| within 2 miles ? | Yes   | 1 | No               | 2 | Yes | 1 | No | 2 |
| " 3 "            | Yes   | 1 | No               | 2 | Yes | 1 | No | 2 |
| " 5 "            | Yes   | 1 | No               | 2 | Yes | 1 | No | 2 |
| " 10 "           | Yes   | 1 | No               | 2 | Yes | 1 | No | 2 |
| " 70 "           | Yes   | 1 | No               | 2 | Yes | 1 | No | 2 |
25. Has cared-for person sisters/brothers elsewhere in Ireland?
- Yes        1                      No            2
- 25(a) Has cared-for person sisters/brothers abroad?
- Yes        1                      No            2

26. Any friend or helper of carer or cared-for person who might be regarded as of special support?

<u>Carer</u>		<u>Cared-for Person</u>	
Yes	1	Yes	1
No	2	No	2

27. If YES, explain and state how far this person lives from carer or cared-for person? \_\_\_\_\_

28. Has carer any relatives living elsewhere in Ireland?

Yes	1	No	2
-----	---	----	---

Has carer any relatives living abroad?

Yes	1	No	2
-----	---	----	---

29. Is carer responsible for looking after anyone else besides cared-for person and those listed in Q.8, e.g. neighbour/friend?

Yes	1	No	2
-----	---	----	---

30. If YES, please state who else is looked after: \_\_\_\_\_

**B. RELEVANT BIOGRAPHICAL SECTION:      HISTORY OF CARING TASK**

31. Can you recall how you first came to assume the task of caring for the cared-for person?

*(Prompt if necessary - Could you cast your mind back to the beginnings of caring, of coming to terms with this pretty full-time task you now carry out. Allow the carer to go back and tell the "story" in his/her own way. Empathy as the tale unfolds, occasional comments to keep the narrative moving and on course. Carefully note the main details, look out for motives expressed, sense of duty felt by carer, fears or other emotions expressed at the initial stages. Guilt or blame may come through. But the carer tells the story in his/her own way and interviewer listens sympathetically, notes the main stages of the story and the feeling with which it is told. Try and note what the parent felt at the discovery that the child was handicapped. And what the carer felt when it became clear that fulltime care of the elderly person was now thrust upon her/him. Try and keep this section to 20 minutes or so. (Three pages were kept blank for the biographies)  
Interviewer should at the end of the story check that the following facts are established if possible. If they are not, the interviewer should ask questions to establish facts.)*

- a) Were there other who might have taken on the task when you did?

Yes	1	No	2
-----	---	----	---

- b) If YES, who were the other/others? \_\_\_\_\_

c) How were you the one to whom the task of caring was entrusted?

---

d) Did carer feel that it was unfair to him/her in any way that this task was placed on him/her?

Yes 1 No 2

e) Length of time carer has carried out this task of caring:

Number of years .....

f) Was there a crisis point where a decision had to be taken between caring for the cared-for person at home or seeking residential care?

Yes 1 No 2

If YES, please elaborate: \_\_\_\_\_

g) Who made the decision to keep the cared-for person at home?

---

h) Who else participated in making the decision?

---

i) Was this before or after or at the very time carer took on the caring role?

Before 1 At the very time 2  
After 3 Not sure 4

j) Did carer feel a special sense of duty to assume this task?

Yes 1 No 2 Not sure 3

k) If YES, please elaborate: \_\_\_\_\_

l) In your own childhood, did your parents look after any elderly person in the home such as a grandparent/handicapped adult or child?

Grandparent		Handicapped Adult		Handicapped Child	
Yes	1	Yes	1	Yes	1
No	2	No	2	No	2

m) For what main reason do you think you go on caring for the cared-for person day in day out? \_\_\_\_\_

---

C

*(Ask all Carers of Frail Elderly)*

32. Can we now talk about the sort of help that the cared-for person needs. Perhaps it is easiest for me to go through a list of things. They might not all be relevant directly to you.

Does cared-for person have any difficulty in:

	On own No diff.	With super- vision	Only with help	W.H O H E L P S ?			
				Carer	Others Name Relation- ship	How Often	Code WHO
Having an all over wash or bathing self	1	2	3				
Washing hands/face	1	2	3				
Putting on shoes and stockings	1	2	3				
Doing up buttons/zips	1	2	3				
Dressing self other than above	1	2	3				
Getting to and using WC	1	2	3				
Getting in and out of bed	1	2	3				
Feeding self	1	2	3				
Shaving (men) Brushing/combing hair (women)	1	2	3				
Cutting own toenails	1	2	3				
Getting up and downsteps	1	2	3				
Getting around house	1	2	3				
Getting out of doors on own	1	2	3				
Taking drugs/medication	1	2	3				
Other difficulties (specify)	1	2	3				

33. In terms of arranging care to meet (personal care) needs, what presents you with the most difficulty? \_\_\_\_\_

34. Have you found ways of solving these difficulties?

---

35. To what extent would you say cared-for person is housebound?

	YES	NO
Bed/Chair Bound	1	2
Permanently housebound	1	2
Able to be left for short periods	1	2
Tends to wander if left alone	1	2
No real risk if left for several hours	1	2

(Ask carers of elderly only)

36. So far we have touched on mainly personal tasks but what about housework, shopping etc.?

Who does? (Go through list)

	Carer	Others Name relationship	How often*	Code WHO *
Cleaning house				
Cooking				
Washing dishes				
Laundry				
Making fires				
Bringing in fuel				
Gardening				
Household repairs				
Household decoration				
Shopping				
Collecting pension				
Budgeting				

CODE:    WHO \*

Cared-for person only	1
Carer only	2
Carer and cared-for person	3
Cared-for person and others	4
Carer and others	5
Others in household	6
Others outside household	7

CODE:    HOW OFTEN \*

Daily	1
Several times weekly	2
About weekly	3
Less than weekly	4
Less than monthly	5

37. Do any of these tasks present you with special difficulties?  
(Record Verbatim)

---

38. Have you found ways of solving them?  
(Record Verbatim)

---

39. (*Ask carers of Handicapped Child only*)  
(S = cared-for person in this case)

IMPAIRMENT AND DISABILITY

I wonder if we could talk a bit about the things S can do and those where there are still difficulties.

(Interviewer: Refer to notes as appropriate)

What about continence?

- |                      |         |       |         |
|----------------------|---------|-------|---------|
| (a) Wetting (nights) | 1 Freq. | 2 Occ | 3 Never |
| (b) Soiling (nights) | 1 Freq. | 2 Occ | 3 Never |
| (c) Wetting (days)   | 1 Freq. | 2 Occ | 3 Never |
| (d) Soiling (days)   | 1 Freq. | 2 Occ | 3 Never |

Mobility and self-care?

- |                    |              |                |                           |
|--------------------|--------------|----------------|---------------------------|
| (e) Walk with help | 1 Not at all | 2 Not upstairs | 3 Up stairs and elsewhere |
|--------------------|--------------|----------------|---------------------------|

(Note: If this person walks by self up stairs and elsewhere, please also code '3' 'Walk with help')

- |                  |              |                |                           |
|------------------|--------------|----------------|---------------------------|
| (f) Walk by self | 1 Not at all | 2 Not upstairs | 3 Up stairs and elsewhere |
| (g) Feed self    | 1 Not at all | 2 With help    | 3 Without help            |
| (h) Wash self    | 1 Not at all | 2 With help    | 3 Without help            |
| (i) Dress self   | 1 Not at all | 2 With help    | 3 Without help            |

Vision, hearing and speech?

- |             |                        |                        |          |
|-------------|------------------------|------------------------|----------|
| (j) Vision  | 1 Blind or almost      | 2 Poor                 | 3 Normal |
| (k) Hearing | 1 Deaf or almost       | 2 Poor                 | 3 Normal |
| (l) Speech  | 1 Never a word         | 2 Odd words only       |          |
|             | 3 Sentences and normal | 4 Can talk but doesn't |          |

Reading, writing, counting?

- |            |           |            |                            |
|------------|-----------|------------|----------------------------|
| (m) Reads  | 1 Nothing | 2 A little | 3 Newspapers and/or books  |
| (n) Writes | 1 Nothing | 2 A little | 3 Own correspondence       |
| (o) Counts | 1 Nothing | 2 A little | 3 Understands money values |

Speech

If this person talks in sentences, is speech: -

- CODE: 1 Difficult to understand even by close acquaintances, impossible for strangers?
- 2 Easily understood by close acquaintances, difficult for strangers?
- 3 Clear enough to be understood by anyone?

He or she does not talk in sentences?

Behaviour

- |   |          |          |      |
|---|----------|----------|------|
| (a) Hits or attacks others  | 1 Marked | 2 Lesser | 3 No |
| (b) Tears up pages, magazines, clothing, damages furniture                                    | 1 Marked | 2 Lesser | 3 No |
| (c) Extremely overactive. Paces up and down restlessly. Does not sit down for a minute        | 1 Marked | 2 Lesser | 3 No |
| (d) Constantly seeking attention - will not leave adults                                      | 1 Marked | 2 Lesser | 3 No |
| (e) Continually injuring self physically, e.g., head banging; picking at sores; beating eyes. | 1 Marked | 2 Lesser | 3 No |

Other handicaps or illnesses

- (a) Epilepsy: Frequency: 1 One or more major seizures per month 2 Occasional seizures 3 No seizures
- (b) Chronic physical disorders/illnesses 1 Yes 2 No  
(specify below)
- .....

In general how would you describe S state of health?

Good or excellent	Alright for age
Fair	Poor

40. Of all these things, which prevents you with most difficulty?

41. Have you found ways of solving these difficulties?

42. I wonder if I could ask how S copes with a range of different tasks around the house and who helps?

Does S have difficulty in	Can do on own or with difficulty	Under supervision	Only with help	Who Helps?*	How Often?*
				R; Anyone else (Name)	
Having all over wash/bath	1	2	3		
Washing hands/face	1	2	3		
Putting on shoes and stockings	1	2	3		
Doing up zips/buttons	1	2	3		
Dressing other than above	1	2	3		
Getting to and using WC	1	2	3		
Getting in and out of bed	1	2	3		
Feeding self	1	2	3		
Shaving (men); combing hair (women)	1	2	3		
Cutting toenails	1	2	3		
Negotiating steps/stairs	1	2	3		
Getting around house	1	2	3		
Getting out of doors on own	1	2	3		

* CODES:	<u>Who Helps?</u>	<u>How Often?</u>
	No help given (not needed) 1	Daily 1
	No help given (needed) 2	Several times weekly 2
	R only 3	About weekly 3
	R and HH members 4	Less than weekly 4
	R and others outside HH 5	Less than monthly 5
	Others only 6	

(Interviewer: List named helpers and their relationship to S)

Helper

Relationship to S

43. In terms of organising these household tasks are you presented with any special difficulties?

---

44. Have you found ways of solving these difficulties?

---

45. During the last week has S been:

	A lot/ mostly	Some- times	Hardly at all/never
Restless	1	2	3
Irritable	1	2	3
Agressive	1	2	3
Obstinate	1	2	3
Affectionate	1	2	3
Appreciative	1	2	3
Forgetful	1	2	3
Impatient	1	2	3
Cheerful	1	2	3
Repeating requests again and again	1	2	3

Can you give me some examples?

---

46. During the last week have you:

	A lot/ mostly	Some- times	Hardly at all/never
Lost your temper with S	1	2	3
Had to restrain S	1	2	3
Been frightened of S	1	2	3
Been embarrassed by S	1	2	3
Found it difficult to leave S	1	2	3

Can you give examples again?

---

47. Are there any problems of incontinence?

Yes 1 No 2

48. If there are, how do you manage?

---



---

D. HELP FROM OTHERS WITHIN HOUSEHOLD:

*(If there is nobody else in the household, go to E. below)*

49. Do other family members help - such as spouse, children, brothers or sisters living within the household?

Yes 1 No Answer 3

No 2 Not Applicable 4

50. Does carer's spouse help?

Yes 1 No 2 No Answer 3

51. If YES, explain what he/she does \_\_\_\_\_

52. Would you note spouse's help as:

Essential 1 Very Important 2 Important 3

Not Very Important 4 Non-existent 5

53. What do other family members who live in household do?

*(List who does what among children, brothers/sisters, or others within the household)*

---

54. Would you describe the contribution of this group as:

Essential 1 Very Important 2

Important 3 Not Important 4

---

E. HELP FROM OUTSIDE THE HOUSEHOLD:

55. Do family members living outside household help in any way?

Yes 1 No 2 No Answer 3

56. If YES, please tell me what they do \_\_\_\_\_

57. Would you note their contribution as:

Essential 1 Very Important 2

Important 3 Not Important 4

58. If NOT, do you feel they ought to help more?

Yes 1 No 2

59. If YES, please elaborate: \_\_\_\_\_

60. Do neighbours give some help in caring?

Yes 1 No 2

61. How many neighbours are involved? .....

62. What exactly do they do to help? \_\_\_\_\_

63. (Read this list fully before allowing interviewee to reply)

Financial	1	
Help with household chores	2	<i>(Note: More than one answer possible here)</i>
Friendship and moral support	3	
Looking after cared-for person for periods	4	
Other (specify)	5	

64. Would you rate the help of neighbours as:

Essential	1
Very Important	2
Important	3
Not Important	4
Non-existent	5

65. Is there something your neighbours could be doing for you, but do not do?

Yes 1 No 2

66. If YES, please explain \_\_\_\_\_

67. Do any voluntary bodies come to your aid?

Yes 1 No 2 Not sure 3

68. If YES, which organizations? \_\_\_\_\_

69. What do they do for you and your cared-for person?

\_\_\_\_\_

70. How would you rate the help given to you by these organizations?

Essential	1	Very Important	2
Important	3	Not Important	4

71. Do you receive help from professional people?

Yes	1	No	2
-----	---	----	---

72. Name the professionals who help: \_\_\_\_\_

73. Do the following come to visit cared-for person?

Doctor	Yes	1	No	2
Public Health Nurse	Yes	1	No	2
Social Worker	Yes	1	No	2
Priest	Yes	1	No	2

74. Does cared-for person have a home help?

Yes	1	No	2
-----	---	----	---

75. How often do the following visit the cared-for person?

	Doctor	Public Health Nurse	Social Worker	Home Help	Priest or Clergyman
When sent for	1	1	1	1	1
Weekly	2	2	2	2	2
Monthly	3	3	3	3	3
Few times a year	4	4	4	4	4

F. CARED-FOR-PERSON:      GENERAL STATE OF HEALTH:

76. How would you describe cared-for person's health?

Generally good	1
Fair only	2
Varies a lot	3
Poor	4
Very Poor	5

77. Does cared-for person suffer from any particular disease?

Yes	1	No	2
-----	---	----	---

78. Can you tell me what it is? \_\_\_\_\_
79. Is cared-for person bedridden?
- |     |   |    |   |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|
80. If NO, for how long does cared-for person get up each day?
- |                     |   |
|---------------------|---|
| For an hour or two  | 1 |
| For 6 or more hours | 2 |
| For normal day      | 3 |
81. Does cared-for person leave the house for a short walk or to sit in the garden?
- |                        |   |
|------------------------|---|
| Never                  | 1 |
| Very rarely            | 2 |
| At least once per week | 3 |
| Most days              | 4 |
82. Could cared-for person do so more often, do you feel, if he/she really wanted to do so?
- |          |   |
|----------|---|
| Yes      | 1 |
| No       | 2 |
| Not Sure | 3 |
83. Are there things which cared-for person does for himself/herself which while good for independence, end up by giving you more trouble than if you did them for him/her?
- |     |   |    |   |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|
84. If YES, what are these? \_\_\_\_\_
85. If you were not available to look after cared-for person, what do you suppose would happen?  
\_\_\_\_\_
86. How does the cared-for person usually spend the day?  
\_\_\_\_\_
87. What does the cared-for person most enjoy?  
\_\_\_\_\_
88. Do you take the cared-for person out sometimes?
- |     |   |    |   |
|-----|---|----|---|
| Yes | 1 | No | 2 |
|-----|---|----|---|

89. If YES, where do you go? \_\_\_\_\_
90. Does the cared-for person go to Church?  
 Yes 1                      No 2                      Very Rarely 3
91. Did the cared-for person vote in the last General Election?  
 Yes 1                      No 2                      Don't Remember 3
92. Do you think that you do things for the cared-for person which he/she could do for self?  
 Yes 1                      No 2                      Not Sure 3
93. If YES, do you think this maybe makes the cared-for person less independent than he/she might otherwise be?  
 Yes 1                      No 2                      Not Sure 3
94. How do you think the cared-for person would feel about going into a residential home for the elderly/handicapped?  
 Would fear it 1                      Would resent it 2  
 Would feel hurt 3                      Would not mind 4  
 Would like it 5                      Don't know 6
95. Would you see it as a good thing if there were residential care for short periods of 2 or 3 weeks to give the carer a rest/break?  
 Yes 1                      No 2                      Not Sure 3
96. How do you think the cared-for person would react to being placed in such a setting for a few weeks each year?  
 Would resent it 1                      Would refuse to go 2
97. Do you think that a time may come when you will no longer be able to look after the cared-for person and so will have to seek a place in a home for him/her?  
 Yes 1                      No 2                      Not Sure 3
98. What do you think would force you to seek fulltime residential care for the cared-for person?  
 \_\_\_\_\_  
 \_\_\_\_\_

G. VISITS FROM PUBLIC HEALTH NURSE & RELIGIOUS MINISTERS:

99. If public health nurse visits, what does she usually do for the cared-for person?  
 \_\_\_\_\_

100. Does public health nurse help you, the carer, in any way?

Yes 1 No 2

101. If YES, please explain:

---

102. Would you rate the contribution of the public health nurse as:

Essential 1 Very Important 2  
Important 3 Not Important 4

103. Does priest bring Communion on First Friday or on one day each month?

Yes 1 No 2

104. Do you think that this visit is important to the cared-for person?

Yes 1 No 2 Not Sure 3

105. If YES, why would you think so?

---

106. How do you feel about it? Does it help in anyway?

---

107. Does it create any difficulties or extra work for you?

Yes 1 No 2

108. Would you suggest any changes in manner or frequency of priest's/  
clergyman's visits?

---

H. MANAGEMENT OF CRISIS:

109. Has there ever been a crisis such as serious illness or sudden illness on the part of the cared-for person?

Yes 1 No 2

110. If so, who came to the rescue?

---

111. Should a crisis arise now or in the future, to whom would you turn?

---

112. Were you ever forced to stay in bed yourself through illness while caring?

Yes 1 No 2

113. If YES, how did the cared-for person manage?

---

114. Is there somebody outside the household on whom you can call readily in a crisis such as illness?

Yes 1 No 2 Not Sure 3

115. If YES, who is this person?

---

116. How would you feel if you were forced to place the cared-for person in a residential setting for good?

Lost 1  
 Very disappointed 2  
 Somewhat disappointed 3  
 Relieved 4  
 Guilty 5

117. What do you think of residential homes for the elderly and for the handicapped?

*(Ask carers of elderly about elderly and carers of handicapped about handicapped)*

---

I. BREAKS FOR PRINCIPAL CARER:

118. Do you get away on your own regularly?

	<u>For a Day</u>	<u>For a Night</u>
Yes	1	1
No	2	2
Rarely	3	3
Never	4	4

119. If YES, about how often do you leave the house?

Daily	1
Every two days	2
A few times per week	3
Once per week	4

120. Where do you go? \_\_\_\_\_

121. For about how long can you be away without upsetting the cared-for person?

---

122. Do you have a regular holiday away from home and from caring?

Every year	1	Most years	2
Some years	3	Never	4

123. If YES, for how long?

A few days	1	A week	2
Two weeks	3	More	4

124. Do you suffer from:

	YES	NO	NOT SURE
Loss of sleep	1	2	3
Exhaustion	1	2	3
Emotional strain	1	2	3
Worry about future	1	2	3
Sense of being trapped	1	2	3

125. Do you have a hobby or pastime?

Yes	1	No	2
-----	---	----	---

126. What is your favourite hobby?

---

127. How often do you enjoy this pastime?

Daily	1	Few times per week	2
Monthly	3		

128. When you leave home for a few hours, who looks after the cared-for person?

---

129. When you leave home for a whole day, who does so?

---

130. If and when you go on holidays, who looks after the cared-for person?

---

131. When you come back to the house after being out, do you feel better yourself?

Yes 1                      No 2                      It varies 3

132. What about the cared-for person, how does he/she feel?

Feels better 1                      Feels much the same 2

Feels neglected 3                      Feels annoyed 4

133. Do you feel you would like to get the opportunity to go out more often?

Yes 1                      No 2

134. If YES, why do you not do so?

---

135. What do you most like about caring for the cared-for person?

---

136. What do you most dislike about it?

---

137. When do you feel best about it?

---

138. What would you say contributes most to keeping you going?

---

139. Would you say overall that you get a sense of fulfillment from it?

Yes 1                      No 2                      Not Sure 3

140. What is the first thing you would do to help and support a friend in your own situation if you were able yourself?

---



J. EMPLOYMENT AND HOUSEHOLD:

152. Do you work outside the home?

Yes 1 No 2

153. If YES, is your work -

Fulltime? 1 Part-time? 2

154. What is the nature of this work? \_\_\_\_\_

155. If you do not work outside the home, is it because you are too taken up with your caring role?

Yes 1 No 2 Not Sure 3

156. Were it not for the caring role, would you be seeking work outside the home?

Yes 1 No 2 Not Sure 3

157. Are you worse off or better off financially?

Better off 1 Worse off 2 Not Sure 3

158. Do you think there are many people who sacrifice a job in order to look after an ageing parent or a handicapped child?

Yes 1 No 2 Not Sure 3

159. Did you have a job outside the home before you began to care fulltime for the cared-for person?

Yes 1 No 2

160. Do you sometimes regret that you cannot work outside the home?

Yes 1 No 2

161. (*Ask women*)

Suppose a good friend of yours came to you with this problem. She had a job as a secretary in an office in town, but now her mother has got a stroke and needs continual care for the foreseeable future. Should she give up her job and mind her mother? Or should she seek some other way out?  
How would you advise her in her dilemma?

---

162. (*Ask men*)

Suppose a good friend of yours came for advice. His mother has had a stroke and needs continual care for the foreseeable future. He works in a drapery shop. Should he give up his job and mind his mother? Or should he seek some other way out?  
How would you advise your friend in his dilemma?

---

K. RELATIONSHIP WITH CARED-FOR PERSON:

163. Would you describe the cared-for person as	YES	NO
a very good companion?	1	2
very close to you?	1	2
someone you like to be with?	1	2
someone you look forward to returning to?	1	2
someone with whom you get on well yourself?	1	2
someone with whom you can have a disagreement or falling out, but can easily restore friendship once more?	1	2
someone who can often be very demanding?	1	2
someone who is difficult to get through to?	1	2
someone who is just not happy and cannot be cheered up?	1	2
someone whom you just could not please?	1	2
someone who never shows any signs of thanks or appreciation?	1	2

164. Does the cared-for person have bad moods?

Yes 1 No 2

165. When he/she is in a bad mood, how do you handle things?

---

166. Do you sometimes lose your patience with the cared-for person?

Yes 1 No 2

167. What annoys you most about the cared-for person?

---

168. Would you say you are closer now to the cared-for person than you were when you took up caring for him/her?

Closer	1	As close	2
Less close	3	Don't know	4

169. Would you say that the cared-for person has changed much since those early days?

Yes 1 No 2

170. Over the last few days, did you have any disagreement with the cared-for person?

Yes 1 No 2 Can't remember 3

171. If YES, could you say what the problem was?

---

172. How did you react? \_\_\_\_\_

173. Does the cared-for person confide in you, share his/her worries, secrets?

Yes 1 No 2  
Don't know 3 No answer 4

174. Does the cared-for person entrust you with financial matters and personal business?

Yes 1 No 2  
Don't know 3 No answer 4

*(Note: If there is no-one else in household, go to Section L)*

175. Has the presence of the cared-for person had any effect on the other members of the family?

Yes 1 No 2

176. If YES, what do you think the effect is?

---

177. Would you think that the presence of the cared-for person has had some good effects on the family?

Yes 1 No 2 Not Sure 3

178. If YES, please explain further: \_\_\_\_\_

179. Are there some harmful effects also?

Yes 1 No 2 Not Sure 3

180. If YES, please explain further: \_\_\_\_\_

181. Do you think that some of the family may feel a bit shy or embarrassed before their friends at the presence of the cared-for person in the house?

Yes 1 No 2 Not Sure 3

182. Does it prevent them inviting their friends around?

Yes 1                      No 2                      Don't know 3

183. Does the cared-for person's presence mean you have more or less visitors coming to the house?

Yes 1                      No 2                      About the same 3

184. Does the cared-for person make visitors feel uncomfortable, do you think?

Yes 1                      No 2                      Not Sure 3

L. MOTIVES FOR CARING:

185. Do you think if you failed to carry out this task that you would be severely criticised by:

	YES	NO
Family	1	2
Neighbours	1	2
The priest/parson	1	2

186. Do you do the caring out of a sense of duty to the cared-for person?

Yes 1                      No 2                      Not Sure 3

187. Or is it a sense of duty to someone else?

Yes 1                      No 2

188. If YES, to whom? \_\_\_\_\_

189. If YES, how do you account for this sense of duty? Where does it come from?  
\_\_\_\_\_

190. Would religion and family be important sources of this sense of duty?

Yes 1                      No 2                      Not Sure 3

191. Of the two, religion and family, which would be the more important source in your opinion?

Religion	1
Family	2
Both equally	3

192. If I were to ask you the crucial question "Why do you do it, and why do you continue to do it when it becomes very difficult?" how would you answer?

---

193. Do you sometimes feel lonely?

Yes 1 No 2

194. If YES, would you say you were

Often lonely? 1

Sometimes lonely? 2

Rarely lonely? 3

195. What in your opinion is the greatest need of someone in your position?

---

196. Do you think you have benefitted personally from your caring role?

Yes 1 No 2 Not Sure 3

197. If YES, in what way? \_\_\_\_\_

198. Do you think your contact with the cared-for person has taught you anything?

Yes 1 No 2 Don't know 3

199. If YES, could you tell me what? \_\_\_\_\_

200. When you grow old, how would you like to be looked after, presuming that you needed fairly fulltime care?

	Yes	No	Don't know	No Answer
In own home alone	1	2	3	4
In home of a son	1	2	3	4
In home of a daughter	1	2	3	4
In residential home	1	2	3	4
Other (specify)	1	2	3	4

201. Which of these would you most prefer?

To be with son 1

To be with daughter 2

To be alone in own home 3

To be in residential home 4

202. Do you think that the next generation will be as willing as this one to look after their ageing parents, parents-in-law, and handicapped members of families?

Yes 1 No 2 Not Sure 3

203. Do you think that young people should be taught their duty to respect and care for the old and handicapped in their families?

Yes 1 No 2 Don't know 3

204. Can people derive benefit and satisfaction from caring for elderly and handicapped?

Yes 1 No 2 Don't know 3

205. Suppose a friend of yours who was caring fulltime for an ageing parent or handicapped child came to tell you that she was at the end of her tether and felt she could no longer cope, how would you deal with her problem?

206. Would you consider that men or women are better at caring for an elderly feeble person or a handicapped child?

Men 1

Women 2

Both equally 3

(Ask carers of elderly about elderly and carers of handicapped about handicapped)

207. Why do you think this is? \_\_\_\_\_

208. Should men be doing more in these kind of situations where a feeble elderly or handicapped person is being looked after in the home?

Yes 1 No 2 Don't know 3

209. Do you think that the care of an elderly feeble person or handicapped child always falls on a woman - with nobody else really doing very much to help?

Yes 1 No 2 Not Sure 3

M. TRANSPORT AND COMMUNICATION:

210. Do you have a telephone?

Yes 1 No 2

211. If you need help in a crisis, what do you do to call help?

212. Do you have a car in the household?

Yes 1 No 2

213. If Not, do you have someone who is willing to give you a lift to town or to the shop?

Yes 1 No 2

214. How far away is your nearest neighbour?

Yards ..... Miles .....

215. How far away is the person you usually contact first in a crisis?

Yards ..... Miles .....

216. Who does shopping for household usually? \_\_\_\_\_

217. Is there a bus from near your home to take you to town?

Yes 1 No 2

218. How far are you from the local post office?

Miles .....

N. FINANCE

Now do you mind if I ask you a few questions about State Benefits?

219. Does the cared-for person receive the Old Age Pension?

Yes 1 No 2

220. Do you yourself receive any financial help?

Yes 1 No 2 Don't know 3

221. If YES, please specify: \_\_\_\_\_

222. Does the Prescribed Relatives Allowance apply in your case?

Yes 1 No 2

Not sure 3 No answer 4

223. If Yes, do you regard it as

adequate 1

inadequate 2

very inadequate 3

224. Why do you say this? \_\_\_\_\_



236. Do you feel that people are more understanding nowadays about handicapped children and their parents than they used to be?

Yes 1 No 2

237. Do you think that the handicapped person/child has a useful purpose in life?

Yes 1 No 2 Not Sure 3

238. How would you see this? \_\_\_\_\_

(ii) (These questions apply only to cases where the cared-for person is an elderly person)

239. Do you believe that the old are less or more respected in to-day's world than in the past?

Less respected 1 More respected 2

240. Do you think that old people still have a contribution to make in the modern world?

Yes 1 No 2

241. If YES, what is this contribution do you think?

\_\_\_\_\_

242. If NO, why do you say this?

\_\_\_\_\_

243. Do you feel that children have a duty to look after their ageing parents?

Yes 1 No 2 Not Sure 3

244. Would you, yourself, like to live to be old?

Yes 1

Yes, if in good health 2

No 3

No, if in poor health 4

Not sure 5

245. Is there an age beyond which you think you would not wish to live regardless of health?

Number of years .....

\_\_\_\_\_

P. MORALE

246. Would you say you are a naturally good humoured person?

Yes 1                      No 2                      Not Sure 3

247. If so, have you remained so since you took on the caring task?

Yes 1                      No 2

248. Has fulltime caring changed you in any way?

Yes 1                      No 2                      Not Sure 3

249. If YES, in what way? \_\_\_\_\_

250. Would you say you are more or less irritable now than when you started?

More 1                      Less 2                      About the same 3

251. Are you more patient now or less patient than you used to be?

More 1                      Less 2

252. Do you tend to tire more easily now than before?

Yes 1                      No 2                      Not Sure 3

253. Do you sometimes feel very much alone and isolated because of your caring task?

Yes 1                      No 2

254. If YES, please explain? \_\_\_\_\_

255. Do you sometimes have fears for the future?

Yes 1                      No 2

256. Why is this? \_\_\_\_\_

257. Are you bored very often by your work of caring?

Yes 1                      No 2                      Sometimes 3

258. Is there anything you would like to add - anything you think important which I have not asked about?

Yes 1                      No 2

259. If YES, what is this? \_\_\_\_\_

\_\_\_\_\_

Q. INTERVIEWER'S COMMENTS:

260. Please write down your own impressions of the carer and how you think he/she is coping with the task

---

261. Would you say the carer is generally:

- not finding task particularly difficult 1
- coping very well 2
- not coping too well 3
- being got down 4
- finding task extremely difficult 5

262. Personality of carer;

- generally cheerful 1
  - not really cheerful 2
  - a bit discouraged 3
  - very discouraged 4
  - other (specify) 5
- 

263. Are there any special problems which the carer has to face?

---

264. Any present need which should be looked after by Social Services or other body?

---

265. Likelihood that carer can continue to care?

Very likely 1      Likely 2      Not likely 3

266. Likelihood that carer would be willing to continue to care?

Very likely 1      Likely 2      Not likely 3

267. Did anything in particular impress you about the carer?

---

268. Did anything in particular put you off, surprise you or shock you about the situation?

---

269. Any comments you may wish to make

