King's Fund

Carers Impact Project in Co Durham

Report on the focus groups and interviews conducted with carers in September 1997

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Appendix 1: Summary of Characteristics

1 Introduction

1 a) Who we spoke to

37 carers were involved in the project in Co Durham, caring for a total of 46 people. 19 of these carers came to one of three focus groups (in Barnard Castle, Newton Aycliffe and Peterlee); 10 carers were interviewed in the Seaham/Peterlee area and 8 in the Teesdale area.

There was a predominance of female carers in both the focus groups and the interviews; overall there were 30 women and 7 men. Half the carers were in the 45-59 age group, and the majority were married. They were most likely to be caring for a spouse (20) or a parent (10). Smaller numbers were looking after a sibling or a child, and one had been caring for her uncle.

Three of the carers interviewed in Teesdale were in fact ex-carers. In two cases, the person cared for was now in residential care and one had recently died. Information was gathered retrospectively from these carers about their circumstances before they stopped caring.

1 b) (i) The interviews

The individual interviews were carried out with the aid of a semi-structured schedule. This was divided into five main sections:

- The history of the caring relationship and the nature of the current caring task
- Pathways to services - how the carers found out what was available and which had proved to be the most useful sources of information
- Carers' experiences of assessment and the implications for support
- Their experience of services
- The impact of services on carers' lives and any gaps identified

On average the interviews took one-and-a quarter hours to complete. The actual time varied according to the complexity of the caring history and the range of services currently received.

1 b) (ii) The Groups

A simple format was adopted for the groups, comprising:

- a warm-up exercise based upon a written "cameo", a fictional account of a carer incorporating some common dilemmas and problems. Breaking into smaller groups, the carers were invited to consider the improvements that were needed in order for the carer's own needs to be met, and how to bring about those improvements. They then fed back their points to the whole group and these were recorded on a flip chart. Previous experience with cameos in a focus group setting had shown that this exercise was helpful in enabling carers to put their own experience into a broader context and to develop a more general perspective on preferred outcomes.

- Individual feed-back from the group members on similar lines but drawing explicitly upon their personal experience. Their replies were recorded on a flip chart.

- A brainstorming exercise around the question, *"If you could improve the situation for carers like you in Co Durham, what would you change?"* Ideas were listed on the flip-chart.

1 c) Presenting the findings

In presenting the findings, we have broadly followed the structure adopted for the interviews. Thus we consider in turn the carers' backgrounds, their experiences of access to services, with special reference to the assessment process, and their views about services currently received. The analysis is based upon the interview data, amplified with material from the focus groups. The 'Key Messages' section at the end summarises the carers' views about desirable outcomes and the factors in their situations which help or prevent these being achieved. Carers' expressed priorities for improvements in current services are then presented.

2 What the carers told us

2 a) Caring background

2 a) (i) The person cared for

The carers who took part in the study were looking after a total of 46 people. Almost half of those cared for were more than 60 years old, and nearly a third were over 75. Most (35) lived in the same household as their carer. Those cared for could not be fitted neatly into client group categories since they were often experiencing multiple problems. Physical disabilities were common in all age groups, and mental health problems were present in a large minority of cases (13 younger people and 6 people over 65 years). There were 10 people with learning disabilities and one with an alcohol or drug problem.

2 a) (ii) Length of time caring

The interviewees had been caring for varying lengths of time. One mother of a 31 year old man with learning disabilities had been caring for him since birth. In most cases, however, caring responsibilities had developed within an existing relationship, in some cases following a sudden illness but more often arising from a gradual deterioration of the person cared for. There were no recent recruits to caring. The minimum period spent caring was two years, and one third of the carers had been caring for more than fourteen years.

Although caring histories were not gathered as systematically from the focus group participants, their own accounts indicated a similar variation in time spent caring but with a rather higher proportion who had been caring for relatives other than their own children for extremely long periods of more than 20 years.

There were several individuals among both the interviewees and the focus group participants who were in effect serial carers, having cared for elderly relatives in the past before assuming their present caring role. Thus one young woman had cared for her grandparents as a young teenager before beginning to look after her disabled mother. She could not remember a time when she had not been caring. Others found themselves caring for more than one relative simultaneously, trying to meet their different and sometimes conflicting needs.

Only a small minority had been conscious of themselves as carers at the beginning of their caring careers. In these cases, a sudden change in the nature of their relationship with the cared-for person had occurred, for example when they had taken in a surviving parent to live with them or when a spouse had been unexpectedly stricken with a bout of mental illness. These life events marked a clear departure from the relationships which had existed before and had signalled a new kind of responsibility. On the whole, however, carers discovered their new identity at a later stage when this was pointed out to them by others or when they realised that their lives were beginning to revolve around their responsibilities for supervision and care. Two women from the Teesdale area said that their self-awareness as carers had stemmed from a caring course which they had attended at a local college. As a result, they had themselves become active in promoting support for carers.

2 a) (iii) Nature of the care needed

There was an enormously wide spectrum of needs among the people cared for. At one extreme were those who were totally dependent upon others for personal care and who had to be tended continuously over the 24 hours. Others were able to manage some tasks for themselves but needed help with aspects of personal care and with household chores and shopping. People with mental health problems were generally fully capable of meeting their own physical needs but sometimes required an element of personal care during acute episodes. More usually, they needed supervision, reassurance and a sympathetic presence. The people with learning disabilities were able to manage their personal care with supervision but also needed continuous emotional support and companionship.

2 a) (iv) Changing demands over time

Those who were looking after elderly people or people with chronic illnesses said that the demands made upon them had increased substantially over time. The burden of physical care had intensified as the condition of the person cared for had deteriorated. In some cases dementia had been superimposed upon existing physical incapacity, adding an entirely new dimension to the caring role. One carer in this situation said that if she had known in advance what would eventually be required of her, she might not have had the courage to take on the care of her elderly mother.

For carers of younger people, the pattern was more variable. Where the person cared for suffered from mental health problems, the carer seemed to be riding a roller-coaster of demands, with peaks of stressful, all-consuming care followed by periods of tranquillity. The unpredictability of this pattern was in itself a source of great anxiety for the carer. One woman who had experience of caring for her husband through serious physical illness and chronic depression at different stages of his life considered that the mental illness imposed a greater strain upon her because it was more emotionally draining.

A number of carers cared for people with progressive illnesses that had begun when the person cared for was relatively young. The demands changed as the person deteriorated, and added to the grief of the carer.

Carers of adults who had physical disabilities but were in a stable condition described a more predictable and continuous pattern of care. Where support was inadequate, stress was constant; however, there were situations in which reliable support had enabled both carer and cared-for to adapt to each other's needs while retaining a measure of independence. Carers of people with learning disabilities had also adjusted to a caring routine. The physical demands upon them had usually eased over time as the person had matured, but a level of supervision was still required, particularly where there were behaviour problems or where medication had to be monitored. Once the person concerned had left school or college, the need to ensure access to entertainment and a social life imposed a new set of demands upon the carer's time, especially in rural areas.

Several carers were in situations of multiple caring. One woman had a son with learning disabilities whom she and her husband had cared for successfully and well for many years. Her husband had then had a stroke, and she was now caring for both, finding the complications of meeting both their needs very stressful.

2 a) (v) Help from family and friends

All the people interviewed considered themselves to be the main carer and more than half said that they were the only carer for the person cared for. Where care was shared, it was usually with other members of the immediate family rather than with friends or neighbours. The help offered by other family members included emotional support and encouragement, regular visits and occasional practical help. It was greatly appreciated, but did not significantly reduce the daily burden of care. Several carers complained that their families showed no interest or had withdrawn from the situation because they felt unable to cope with the needs of the person cared for. Being left to cope alone was the source of considerable anguish and resentment for the carers concerned, and had sometimes resulted in tension and rows between family members to add to the stresses of caring.

2 a) (vi) What got them down

Some of the things that got the carers down related directly to the condition or behaviour of the person cared for. *"Seeing someone you love in pain"* was the worst part of it for one carer and her feelings were echoed by several others. There were many examples of behavioural problems or negative attitudes which carers found hard to accept. These covered a wide range, from fits of violence and aggression to *"bloody-mindedness"* and *"never saying thank* *you"*. One carer compared her mother's constant shouting to Chinese water torture and yet panicked whenever it stopped.

Others found the attitudes of others more difficult to cope with than the caring itself. Professionals who patted them on the back while offering no tangible support and family members who took them for granted were equally resented. Unhelpful and hurtful attitudes in the population at large were cited by several carers. One woman described the impatience of people in the queue at the supermarket whenever her daughter with learning disabilities tried to manage the shopping on her own. Another made the more general complaint that *"I'm a second class citizen. Because I'm a carer, it's assumed I can't do anything else"*.

The lack of spontaneity in life was regretted by many carers. Any outing had to be meticulously planned in advance and usually depended on a number of arrangements all falling into place, any of which could go awry. They wanted just to be able to decide to go out and go. Other carers were depressed by the fact as one carer put it: that her life was at the bottom of the list; and another said that her life was over at 40.

2 a) (vii) What they enjoyed

Only one carer said that she had enjoyed nothing about caring, admitting that she had never got on with her mother anyway; and a few said that there was not a lot they enjoyed. For the others, a degree of satisfaction and enjoyment came from meeting the needs of someone they loved, from fulfilling a sense of obligation and from the conviction that they were providing a quality of care that was superior to that offered by any alternative. Sometimes the pleasures were quite small - having a good day, sleeping the whole night through or receiving a welcoming smile - but were nonetheless important in helping them to keep going.

2 b) Access and assessment

2 b) (i) Access to services

More than half the carers interviewed said that they did not have a clear idea at the beginning about the help and support which they needed. They had had no occasion to find out about services and did not know where to begin to look. One carer of an adult with learning disabilities said that there simply were not any services available until the Community Learning Disabilities Team had been formed when her daughter was a teenager; prior to that, parents had just assumed that they would have to struggle on their own.

The carers who said that they had known about sources of help were those who had had previous experience of caring or who were professionally involved in the caring services.

A majority of the carers reported that their first contacts with support services were made through the health services (GP or medical or nursing staff in hospital). These contacts were usually triggered by a specific event, such as a hospital admission for the person cared for. Some of the others had first made contact with the Social Services Department in order to seek a specific service, such as day care. Other first contacts were with a carers support worker or other voluntary organisation.

On the whole, the carers had found their first contacts useful. Emotional support appeared to be as important at this stage as the information about the services available. Thus one woman whose husband had become acutely mentally ill said the main benefit had been the feeling that she had someone on her side and was not alone with the illness. Another who had begun to look after her mother as a teenager said, *"She was really good. She listened. She didn't provide me with anything tangible but she provided the support which saw me through".*

Looking back, several carers considered that the actual information which they had been offered by social workers had been limited. Sometimes this had reflected the contact's own lack of knowledge of the wider spectrum of services. Thus one carer recalled how her social worker had failed to identify the Independent Living Foundation as a source of financial assistance for her mother despite the severity of her disabilities. Others felt that social workers were, perhaps unconsciously, functioning with a dual agenda of wanting to be helpful and supportive while at the same time restricting demand for services which were perceived to be in short supply. One carer, for example, recalled being told during her first interview with a social worker that the Department's budget for home care was extremely limited and that it would therefore be necessary to *"explore all other avenues"* before providing it. Another said that although she got on well with the social worker and community psychiatric nurse and had great faith in them, experience had shown her that *"unless you push, nobody tells you".* More acerbically, a third carer said that a better name for Social Services would be Secret Services. This experience of having to struggle to find information about the right kind of help was echoed in the focus groups where there were complaints that Social Services tended to tell carers only about those things which they felt able to provide, whether or not they were the best means of meeting the need in question.

In contrast, carer support workers were praised for having comprehensive information at their fingertips and for adopting an open and positive approach to sharing it. One such worker was described as *"the key to everything"* by a grateful carer who also appreciated her conscientiousness in returning calls promptly. Their position outside the direct line of service provision appeared to enable the support workers to develop an overview of services and an impartial approach to offering information and advice.

Several carers considered that they had received better advice and information from other carers than from workers within the statutory services, although they recognised that having to rely on personal contacts was far from ideal because of the random way in which information was distributed. Those carers who had contacted voluntary organisations with a specific remit such as MENCAP and the Multiple Sclerosis Society had found them helpful and informative.

2 b) (ii) Social Services Assessments

Over two thirds of the carers interviewed reported that they had had a discussion with Social Services staff within the last two years about the help and support they needed. They did not necessarily identify these encounters as "assessments", although the term is used here as a convenient shorthand. In several cases a meeting or visit had taken place within the past few weeks. Some carers described a regular pattern of contact while, for others, the assessment had been an isolated event.

The context and content of the assessments varied quite considerably. Often they had been experienced as little more than an informal chat in the carer's own home; on other occasions they had taken place in quite a formal setting, such as a hospital ward, and had involved several different professional staff. Sometimes the purpose had been to review a specific aspect of the caring situation - perhaps the introduction of a new piece of equipment or additional home care hours. This type of assessment was quite likely to have been initiated by a request from the carer. More rarely, the assessment had taken the form of a general review of the circumstances and needs of the person cared for within an overall care plan. In such cases, the meeting was more likely to have been arranged by the social worker.

The carers were generally positive about the attitudes of staff undertaking assessments. *"Very helpful and caring"* was a typical comment. One carer was, however, extremely critical about the way in which her meeting had been handled since it had not only failed to produce any positive solutions but had also led to a leak of confidential information about her case within the Social Services Department. She felt that the workers involved had only heard what they wanted to hear rather than being open to what she wanted to communicate.

There was considerable vagueness around the recording of the assessments. Most carers remembered that a written record had been made of the needs of the person cared for but only one had received a copy. Three of the carers recollected that their own needs had been written down and, once again, no copy had been given. Thus the decisions that had been reached tended to have the status of informal understandings rather than public statements of intent.

Most carers who had received an assessment said that it had been useful in terms of the practical outcomes which it had produced. The opportunity which it had offered for their voice to be heard was also valued. As one carer said, *"My own feelings were taken into account for the first time after screaming for so long".* Practical outcomes usually involved small additions of support in the home, such as extra meals-on-wheels, home care or shopping. In one case, however, a carer was able to negotiate an end to her caring role which had become so burdensome that it threatened her own health and was affecting the well-being of her children. By imposing her own limits on the amount of care she was able to offer each day, she was able to demonstrate that the care plan which had been constructed to support her mother following hospital discharge was not viable. A decision was therefore taken that her mother should enter residential care.

In the two cases where the carer was dissatisfied with the assessment, the practical outcome had been unsatisfactory and the procedure itself had been judged faulty. One said that apart from giving her an opportunity to vent her anger, the only difference it made was that two possible extra financial benefits had been eliminated. She considered that other suggestions which had been made for augmenting her mother's existing care package were inappropriate. The other carer considered that the Occupational Therapy assessment which had been undertaken to ascertain her mother's need for a stair-lift was too narrow in its focus and too uncertain in its outcome. She believed that her mother should have been offered a full community care assessment, and that the specific decision about the stairlift should not have been passed to a care manager who did not know the case. Three carers were not dissatisfied with the assessment process but said that it did not produce useful outcomes for them. Two of these carers had been recommended to take more breaks from caring but found it inconvenient and expensive to do so; another carer said that *"they talk but nothing gets changed".*

An explicit attempt to speak separately to the carer and the person cared for was made in only two cases, and in an additional five cases only the carer was spoken to as the person cared for was in hospital, residential or day care. Nonetheless, most carers felt that the procedure had been fair to both parties, with any conflicts of interest acknowledged and resolved. For example, one carer reported that his father had accepted home care, even though he would have preferred not to, because he had been persuaded that there was no other way to help him cope in his own home. He later came to enjoy the daily contact which the visits of the care staff provided. Where the people cared for were incapable of independently expressing a view or unwilling to do so, the carers acknowledged a responsibility to interpret on their behalf and tried to guard against the danger of imposing their own judgements. On the whole, however, the carers considered that the assessment process was focused more upon the user than the carer and that there was a greater risk of their own views and needs being sidelined. One pointed out that carers can be as isolated and housebound as the people cared for and that the assessment process should take equal account of their needs and the impact upon their families.

2 c) Carers' experience of services

2 c) (i) The range of support received

The people who were interviewed gave a detailed account of the services they received, and at each focus group the participants gave descriptions of their circumstances, though these were inevitably briefer and more sketchy than the interviews.

The services received varied in intensity and complexity depending upon the level of dependence of the person (or people) cared for, rather than on the needs of the carers, although in a number of instances emergency packages of care had had to be organised when the carers had had health crises of their own.

An example of someone receiving intensive domiciliary care was a young man with physical disabilities, being cared for at home by his parents. Care workers attended to him three times a day, every day, for all his personal care needs, and he had sitters overnight two nights per week and two mornings. Another woman was receiving a complex package of care, organised by her daughter, with the help of resources from the Independent Living Fund. At the other end of the spectrum was a woman with physical disabilities who was receiving no direct care services at present while her drug regime and incontinence were being monitored. Equipment and adaptations to the home were significant components in the care of almost all people with physical disabilities, although, once again, the complexity of the provision varied from person to person.

For people with mental health problems, the level of care varied considerably with changes in their condition. For example, one carer whose husband was comparatively well at the time of interview said that they had used homecare and a crisis telephone line in the past, and had received the support of a social worker, but that none of these applied at present. However, her husband was seeing a community psychiatric nurse and had regular appointments with a consultant psychiatrist and a cognitive therapist.

Most of the people cared for had some kind of day care outside the home, and this was usually for part of the week only (one, two or three days). This was valued highly by the carers (one said that it was her lifeline) and they often expressed a wish for more days. Some of the carers of those who were not using day care at the moment were looking to use it in the future. The day care services were often quite complex and involved going to different places on different days. This did not present a problem once the person cared for had got used to the situation and knew what to expect; but the importance of a gradual introduction to day care was emphasised in the focus groups and in some of the interviews.

Respite care was a feature of the lives of most, but not all of the people cared for. Three of the carers receiving no respite had been offered and encouraged to take it. However there were inhibiting factors of cost, and in one case the person cared for's reluctance to go, and in the other, the carers reluctance to trust the quality of care provided. Respite care was provided in a wide variety of settings including hospital, with a family, 24 hour domiciliary care, and residential homes.

Community nursing services were a regular feature of the care for some people, but more often nursing care was for short periods only, for example following discharge from hospital.

Social work services were a background presence in the lives of many carers, but were usually called upon only for routine matters such as arranging respite care. Emotional support for a number of carers was provided by voluntary organisations, including the Dysphasic support group, the Stroke Association support group and MENCAP. The Teesdale carers had been recruited through the Teesdale Carers Centre which was identified as a source of emotional support as well as practical advice.

In the Peterlee area, the interviewees had been contacted through Crossroads. It was not surprising, therefore, that the sitting service provided by Crossroads was an important feature of these carers' support systems. By comparison, few of the Teesdale carers were currently using a sitting service.

2 c) (ii) The right level of support

One carer summed up the attitude of many others when she said that she would like more support but was grateful for what she got. These carers gave the impression that the level of support which they received was enabling them just to keep their heads above water. Some felt that this lifestyle was sustainable while others were fearful of going under if their circumstances took a turn for the worse.

A smaller number of carers were adamant that the level of support they had was inadequate. Those caring for people whose mental health problems had caused behavioural difficulties seemed particularly likely to feel unsupported. *"I was a one person psychiatric hospital"*, said one carer who also remembered screaming down the phone in order to obtain some care.

More day care was a priority for many carers. Those caring for older people with Alzheimer's Disease in the Peterlee area would have liked to extend their access to specialist day care from three days to five. A carer in the Teesdale area reported that she had lost access to psychiatric day care once her mother had been "signed off" by the local hospital, after which she had been told that her mother was too difficult to be accommodated in an ordinary day centre. Her only solution was to purchase care privately at a local nursing home for one day a week. Alongside requests for more specialist day care, there was an urgently expressed need for age-appropriate care for younger people with physical disabilities. One man with a brain injury went to a centre for people with Alzheimer's because there was nothing more suitable for him, and a woman with MS in her early fifties had for the past twelve years been attending a centre catering for elderly and infirm people.

Similarly, some carers identified a need for respite care which was better adapted to cater for people with specific physical needs, such as brain injury or spinal injury. Having the right *kind* of support would have enabled them to feel that they were also receiving the right *amount* of support.

For several carers, cost was a barrier to extended use of sitting or respite care. This was either because the direct cost of receiving the service was judged to be too high or because - in the case of respite care - they feared that existing benefits would be compromised. Thus, for example, one carer who used a "brilliant" respite care facility at an EMI unit said that she had now achieved her maximum entitlement (two weeks' care every six weeks) and that any more care would result in loss of benefit.

2 c) (iii) Choice

Carers were asked questions in the interviews about how much choice they and the person cared for had had over the services provided, and whether or not they had been offered alternative providers of services. One carer had decided to take control of her mother's care by organising her own package with several interlocking components; however, she reported that she had little choice over the individual components, such as day care or respite care, because of the limited options available. Most carers did not feel that they had had any choice at all over the services which they received. Some did not mind, as long as what they did get was of good quality and appropriate to the needs of the person cared for. However, others were critical of professional attitudes which implied a "take it or leave it attitude". Thus one carer complained,

"You don't get any choices. They say what's available and that's it. They say 'We can give you three hours a week' whether or not you can use it. They need to ask the carers what they really need and how their lives would change with those services."

Location was identified as a factor limiting choice, particularly in the more rural parts of Teesdale. A scarcity of day care and respite care, particularly for people with specific physical or mental health needs, was considered to be an unavoidable aspect of living where they did. Those carers who felt that they had expressed a choice were more likely to have turned down a particular service than to have made a positive choice from a range of options. An example is provided by a carer who had rejected an offer of respite, even when strongly recommended to accept it for her own sake.

Most carers were not offered choices between alternative providers, and they tended to believe that such alternatives were simply not available. One carer had visited several nursing homes, but had decided to reject nursing home care as an option. Some people used a number of different day centres concurrently, rather than as alternatives.

The carers reported that the welfare of the person cared for was always central to the decisions which they made about services. The tensions which sometimes arose between their respective wishes could usually be resolved by compromise. In some cases, however, carers had discontinued or changed services in response to unhappy reactions on the part of the person cared for. Even where communication difficulties were present, carers were usually confident that they were sufficiently sensitive to the moods and behaviour of the person cared for to judge when care had been unsatisfactory.

Most carers agreed that the people they cared for had no direct choice over the support they were receiving, partly because of the lack of options open to them, but often, additionally, because their mental or physical health did not enable them to express a view. In a few instances, the person cared for had clearly expressed wishes that had been taken into account; for example, one man attended a day centre one day a week only, although his carer had been keen for him to accept an offer of an extra day. He did not really want to go at all, and so the single day was a compromise.

2 c) (iv) Current problems with services

➧ *Insufficient amounts of support*

Day care and respite were the services often mentioned as being insufficient. In the Peterlee area, day care for people with Alzheimer's Disease was a particular instance of a service that carers wanted extended. Respite care for adults with learning disabilities was in short supply, and seemed to be dependent upon the availability of family carers.

Day care for people under 65 years old was described as a "massive void."

Social activities and entertainment for young adults with learning disabilities during evenings and weekends were identified as another gap, particularly by carers living in rural communities.

Specific support for children in families where an adult is suffering from mental health problems was seen as a pressing issue by one carer who felt that her son had suffered considerably during acute phases of her husband's illness. She considered that children in such situations should be considered to be in need and receive an appropriate response from children's services.

➡ *Inadequate response times*

Delays on the part of Social Services in responding to the help requested were mentioned in both the interviews and the focus groups and were a source of acute frustration. Often the delays were experienced in relation to the supply of equipment. One woman who had requested a bath aid reported that a long period had elapsed before the assessment had taken place, followed by another period of silence which was punctuated only by her intermittent and unsuccessful attempts to contact the occupational therapist by telephone. She was repeatedly told that the person she wanted to speak to was unavailable until, in desperation, she gave a false name and was put through directly. Once the bath aid was supplied, it took another two months for her housing association to install it. Another carer had resorted to contacting her MP when a year had elapsed since contacting Social Services for equipment for her tetraplegic husband. Delays also dogged some carers' search for respite. One man reported that Social Services simply had not responded to his enquiries, and he feared that respite would have become a crisis issue by the time that they did.

A specific issue for carers of people with mental health problems was the time taken for services to respond to a change in the condition of the person cared for. One carer felt that her husband was expert at disguising his symptoms to the professionals in charge of his care, even when she was perfectly aware of a deterioration. She considered that valuable time had been lost through their failing to make use of her own expert knowledge.

➡ *Services not appropriate*

The availability of services which catered for the specific needs and abilities of the person cared for was an important issue for carers. Some wanted services with a more specialist professional input while others pointed to the need for a higher general standard of training and awareness among care staff so that they would become more sensitive to the particular requirements of each individual. Inappropriate provision was once again raised in relation to equipment and adaptations, with carers reporting that what was supplied often seemed to bear more relation to the resources available than the expressed needs of the carer. This disparity was vividly illustrated by the experience of one carer who had contacted Social Services about an adaptation to her bathroom only to be told that there was a two-year waiting list. When she pursued the matter again, the OT came out to assess her for grab rails. Another man who enquired about an adaptation to his kitchen was only offered a special stool.

➡ *Issues of quality*

Carers' views about the overall quality of services were variable. There were many satisfied customers who had confidence in the support they received and for whom it had become an essential part in their own caring routine. Crossroads was frequently singled out for praise, and the key ingredients appeared to be the provision of trained sitters with flexible attitudes and a genuine interest in the person cared for. Believing that the Crossroads carer was fully equipped to cope with the situation at home gave the carer peace of mind and added to the value of the break. Many positive experiences were also reported in relation to day care, respite care and homecare.

Where lapses in standards occurred, however, they caused considerably anxiety and undermined confidence in the provision. Carers worried particularly about respite care because it involved a complete transfer of responsibility, and they were sensitive to any signs of carelessness or neglect. One carer was shaken when an administrative slip up resulted in a failure to deliver her mother home from a respite holiday home which she had visited on several occasions. Another felt angry when the person cared for was sent home from hospital respite with severe diarrhoea and, on another occasion, missing some of his clothes.

Complaints about homecare centred on the lack of training for staff. Care workers were reported to be frequently young and untrained, and often with little job experience of any kind. When challenged by a crisis - such as, in one case, a diabetic collapse - they were quite incapable of judging the correct response.

➡ *Cost*

The cost of services was clearly a burden to most carers. Most of them accepted their full entitlement of service at zero or minimal cost but did not take opportunities for extended access because of the extra costs involved. One carer said that you would have to win the lottery to be able to go out and have a social life because sitting would cost £8.80 per hour, over and above the evening per fortnight that she got free.

The costs of respite care limited the amount that carers could take up, even when encouraged to do so.

The worries about cost were exacerbated in some cases by carers who saw the allocation of services as unfair, with some people getting more services free of charge than others.

➡ Medical input to day care facilities

A few carers reported that their access to day care had been restricted by regulations which prohibited medical interventions by care staff. For example, one man whose wife had required regular injections was told that these could not be given by day centre staff, and when the consultant changed the medication to capsules, Social Services continued to refuse to take responsibility for administering them. The lack of an input from health had in effect denied his wife the opportunity to attend day care. *"We are being excluded and she is being deprived of social contact,"* was his summary of the situation.

➡ Help with lifting

Several carers had encountered inflexible approaches among care staff to the problems of lifting the cared-for person, both at home and in day care. They felt that health and safety concerns were addressed almost exclusively at paid staff, leaving the carer vulnerable and unsupported. The levels of staff provided by homecare agencies were often insufficient to manage the lifting without the assistance of the carer. One man had eventually persuaded the homecare service to provide two carers for the morning and the evening, but this was only after an initial refusal and several complaints on his part. His comment was,

"You need to shout loudly and high up. Those who shout the loudest get the services."

➡ Travel and transport

Physical access to services was often difficult for carers, particularly in the more rural parts of Teesdale or where carers lived at the intersection of the three health districts which cover the county. One carer in the latter position reported that she had had to travel long distances for wheelchair clinics in the different districts. A few carers were reliant on specialist facilities outside the county, involving long and difficult journeys. An example was the carer of a man with mental health problems whose appointments at a clinic in Newcastle necessitated a cross-country journey which often left him exhausted, particularly when he was in a depressed state. Some carers needed transport to be provided in order to access services, and one was severely critical of the ambulance service which had not only transported her severely disabled mother to hospital at high speed (although it was not an emergency) and in an entirely unsuitable seat but had caused her to wait three hours for her return journey.

➡ *Continuity*

Continuity of the personnel providing care was generally considered to be important, but most particularly so where care was mediated through a one-to-one relationship which involved a degree of intimacy between the person cared for and the paid carer. The personal care offered by the homecare services fell into this category, and both carer and cared for disliked a rapid turnover of workers, preferring to rely on the same person or, at most, a small team. The opportunity to provide continuity and quality of care was a principal motivation for the carer who had organised her own care package, recruiting a team of carers to her own specifications in order to meet both her mother's physical and emotional needs.

In a rather different context, continuity of contact was extremely important for people with mental health problems for whom their personal relationship with professional staff was of central importance, both at times of crisis and during the intervening periods of greater stability. In one case, a change in Social Services district boundaries had deprived a man of continuing contact with a social worker whom he liked and trusted. He had refused to accept the replacement, and the whole episode had caused him distress which, in his carer's view, could have been avoided by a more flexible and pragmatic approach by the Department. For another man, it was extremely important that his consultant psychiatrist shared his Christian views, and the imminent retirement of his present consultant was a source of some anxiety.

2 c) (v) Help from the GP

Most carers found their GPs helpful but within carefully defined limits. Typically, the GP did not offer regular contact and support but would respond to requests for visits, and refer to a hospital consultant where necessary. Many carers did not expect more but some said that they wished their GP would be a little more forthcoming with advice and perhaps occasionally ask after their own well-being. GPs did not always seem to recognise the practical difficulties which carers faced in getting to the surgery and which consequently limited their access to care. One carer who looked after both her mother and her sister who had learning disabilities found it impossible to go to the surgery, even for a routine appointment, because of the difficulty of getting them all there. Although the GP was willing to visit, he would stay only for a few seconds.

GPs were not considered to be good sources of information. Often the carers knew more about the medical conditions of the people they cared for than the doctor did. One carer said that her doctor was out of his depth and admitted it. Another reported that the onset of her mother's dementia was diagnosed as depression.

Despite this generally low level of carer awareness, there were a few practitioners who offered both a high quality of personal care and a flexibility of approach which maximised the benefits for the carer. An outstanding example was a GP in Teesdale who was commended as "wonderful" because of his concern for the carer, the speed of his response in a crisis and his willingness to mobilise the remainder of the primary health care team on her behalf.

2 c) (vi) Liaison between services

Most carers considered that service providers did not liaise with each other. The general perception was of the separate services working within their own patch and sometimes guarding their territory protectively. Liaison was often better within a sector (for example, between social workers and the homecare service) than across sectors. Communication between GPs and Social Services was considered to be almost non-existent.

A lack of liaison was not an issue for the carers so long as services continued to be supplied reliably. When communication broke down around specific arrangements, however, considerable anxiety and inconvenience resulted. One example was provided by a carer who looked after both her husband and her son. Her son had learning disabilities and had to be met at the bus stop on his return from the day centre. When her husband had a hospital appointment, she worried about not being home in time to meet her son. Another carer reported that when her daughter with learning disabilities was in respite care, no transport had been provided to take her to her regular day centre despite a specific request having been made.

On the positive side, there were reports of good communication between CPNs and consultant psychiatrists which promoted a satisfactory flow of information about the changing condition of people with mental health problems, giving their carers a greater sense of security.

2 c) (vii) The impact of services

The carers interviewed were asked questions about the impact of services upon themselves and the people that they cared for. They were specifically asked if the services received gave them more time for themselves; whether the person cared for benefited from the services received; and about the impact of services on their relationship.

Carers valued the practical assistance which services offered. Extra help coming into the home alleviated some of the physical burden of caring and allowed the carers to achieve a better quality of care for the person cared for (for example, by being able to give them a bath or lift them more easily from bed to wheelchair). Assistance with lifting and handling was vital where the carers had back problems of their own. Several carers would, however, have welcomed a recognition on the part of the homecare services of the need to provide enough staff to manage the lifting independently. The carer would then be able to be "off duty" while the care workers were in the home.

Day care and respite gave the carers time off but this was not usually an opportunity to rest and relax. Most carers spent the time doing necessary chores, such as shopping and housework, that could only be done satisfactorily while they did not have caring responsibilities in the home. Maintaining links with other members of the family and with friends was another important preoccupation. Thus one woman who cared for her husband and son with learning disabilities, used some of the time when they were both at day care to visit another son who had physical disabilities, and did not live with her. Some carers had sitters in the evenings on a regular basis that enabled them to maintain a social life.

Only two carers had a sufficient level of support to enable them to maintain a full-time job. One of these said that going to work was her way of keeping her sanity. Most people, she said, stop work and go home to relax, but her work started when she got home. The other had independently co-ordinated a complex care package both in order to meet her mother's needs and to give herself time to pursue a demanding business career.

When asked about the difference that services made to the people they cared for most carers emphasised the importance of going outside the home to day care and respite care. The people cared for enjoyed the change of scene, the variety of people they met, and, for some, the activities that they were able to engage in. For people with mental health problems, having a "safety net" of professional back-up in a crisis was extremely important.

Many carers found it quite difficult to decide whether the services they received made a difference to their relationship. Often these were cases where the person cared for was suffering from dementia and the relationship was one of total dependence. One carer said *"I don't know about our relationship, but it makes me feel better"*. Rather more graphically, another carer said that, without services, *"She'd have been dead because I would have killed her!"*. Many carers expressed feelings of relief and relaxation, and some said that they were more patient as a result. When the person went to day care or into respite, it refreshed their relationship by giving them something to talk about when they came home. One young woman said that resentment would have crept into the relationship if she had not been able to access services and she would probably have come to see her caring responsibilities as an obstacle to her own fulfilment.

3 Key Messages

Factors which help and hinder achieving positive outcomes (some of the factors are entered under more than one heading)

Desired Outcome	Factors which hinder	Factors which help
Good communication between carers and service providers	Phone calls not returned No contact with senior managers	Carers articulating the help they need Carers being listened to Good communication within the Social Services Department Carers to be consulted Being given straight answers
Easy access to services	Unnecessary pressures from filling in forms Having to fight for everything Constantly hitting your head against a brick wall Not fulfilling commitments made in the Community Care Charter Slow response to request for visits No help forthcoming even when the person cared for is a priority Disputes between Social Services and health services over areas of responsibility Delays in the delivery of services because of funding	To be able to get hold of people Even handed approach to different people Those who shout loudest get the services

Desired Outcome	Factors which hinder	Factors which help
Good access to information	Asking about alternative services and nobody knows	Being told what is available
Emotional support		Someone to look after you Help from members of the family Someone to talk to Talk to someone about the decisions to be taken Getting together with other carers
Having a life of your own	Person you care for can be selfish and manipulative	The person cared for must be happy too Importance of "Finding out you're a human being again" Carers are entitled to a life of their own Paid employment - for fulfilment More day care and respite care The need to work out what is right for the carer and the person cared for. Not being expected to care regardless of your own health or circumstances The carers life is more important than the person cared for. Carer learning to ask for help Person cared for being responsible for themselves.

Desired Outcome	Factors which hinder	Factors which help
Time off	Person cared for refusing sitting service Carer not letting go Cost of respite care	Carers to plan and make up their own minds You have to have peace of mind Sitters have to be a friend, to get to know the family
A decent income	Financial pressure Costs of caring Costs of services Delays in payments from ILF	
Reliable and appropriate services of acceptable quality	Having to use the commode in the sitting room - no dignity	Appropriate equipment Using the collective voice of carers to campaign for services Rules about Health and Safety at work applied to the home. Continuity of care workers Services to recognise the whole person

3 b) Carers views on improvements needed in Co Durham

3 b) (i) Advice and information

- ➧ A more proactive and comprehensive approach to information giving is needed on the part of professional workers. Carers often get the impression that information is being rationed in order to contain demand. Social Services appears to be particularly guilty of this restrictive approach. Information needs to be taken to the carer and sympathetic help offered in interpreting their requirements.

- ➡ The information base of social workers and other advice givers should be enlarged to include solutions which lie outside the remit of local statutory services. Carers need information about a wide range of options in order to access the support which best fits their individual circumstances.

- ➡ There is enormous scope for improving the quantity and quality of information provided through GP surgeries. At present GPs and other members of the primary health care team are not functioning as point of referral to social care services.

- ➡ The independent information service provided by the Teesdale Carers Centre is valued by carers because it offers an instant overview of local provision and a helpful context for seeking help. This model could perhaps be adopted in other settings across the county.

3 b) (ii) Responsiveness of services

- ➡ Quality standards are needed to improve the way in which Social Services staff handle approaches from carers. The study uncovered a widespread failure to return telephone calls and to keep in touch about progress on agreed lines of action. This indicated almost a bunker mentality on the part of some staff. Carers experienced considerable frustration and annoyance as a result, several complaining that they had had to engineer a crisis in order to elicit a response.

- ➡ A more explicit focus on carers needs is required within the assessment process. Carers feel that present procedures are user-centred and fail to take account of the carer as being more that just a component of the caring situation.

- ➡ The assessment process sometimes needs to be widened to include carers outside the immediate family situation who are providing essential support. A focus which is too narrow may fail to take into account the whole support system upon which the cared for person relies.

- ➡ Carers recognise the value of care plans but would like some formal mechanism for monitoring them and for coping when they fail. A collapse of one element of a care package can spell disaster for those involved, and swift remedial action is required.

- ➡ Carers of adults with mental health problems emphasise how important it is that services recognise the episodic and unpredictable nature of their caring responsibilities. Responses need to be adjusted to this changing pattern. If services are not flexible, they cannot meet the needs of the carer or the person cared for.

- Carers would like a speedier and more honest response to their requests for equipment and adaptations. Many have felt fobbed off with inappropriate items or have been made to wait for an unacceptable length of time before receiving the help they need. Service responses too often appear to be driven by resources rather than by carers needs. Carers quite reasonably feel that if they have been assessed as needing a particular item of equipment or an adaptation, they need it then, rather than a year later.

- Carers would like to see a greater responsiveness and better communication skills on the part of GPs and hospitals. In their experience, the medical profession shows little regard for the carer and little insight into the problems of caring from day to day.

- Sometimes quite small increases in speed and efficiency would make a difference to carers. For example, a quicker reporting of the results of urine tests would prevent delays in starting appropriate treatment.

- Carers would like a commitment from the Health Service to deliver the Patient's Charter locally and to identify particular individuals who could be held accountable.

- Emergency support was an issue for most carers. Unless they had reliable back-up, they felt that any interruption in their own capacity to care would result in a crisis for the person cared for. Their preferred option would be to have a nominated worker who was known to the person cared for to take on the co-ordination of care in these circumstances.

- Carers want to be treated fairly as individuals but also to be assured that there is an equitable distribution of resources between different geographical areas and groups. They feel uncomfortable about having to compete for resources by shouting more loudly than others.

- In general, carers want to be taken seriously and listened to. They would also like more vigorous efforts to be made to contact "hidden carers" who continue to care in silence.

3 b) (iii) Overlap of services

- Carers felt that the operational boundaries between Health and Social Services were interpreted too rigidly by front-line staff. There was too much guarding of service boundaries and too little willingness to pool resources and expertise in order to address needs in a holistic fashion.

- The lack of a Health input into Social Services day care facilities in order to administer medication was identified as a particularly damaging example of poor communication since it resulted in the exclusion of people who would otherwise have benefited from the service.

- Carers who had experienced the transition between children's and adult services wanted to see improvements in forward planning to meet the individual educational needs of young people post 19.

- Easington is serviced by three health authorities which complicates the lives of several carers who found that they had to travel long distances in order to access certain services, such as wheelchair clinics. They wanted an integrated service which offered accessible, local provision.

3 b) (iv) Quantity and appropriateness of services

- More staff on geriatric wards would be a significant improvement for many carers. Some had had to visit several times a day in order to feed the person they cared for because the staffing levels were not sufficient to give the attention needed.

- Carers would also benefit from improved staffing levels for homecare services so that the person cared for could be lifted by the care workers without the carer always having to be present to assist.

- Good access to transport is crucial to carers and presents a particular problem for those living in rural areas. Better public transport, especially a more frequent bus service, is needed, along with buses that can accommodate disabled persons' scooters. Carers would also like more flexible transport options, such as Dial-a-Ride, so long as they are available when required. A regular and reliable pick-up and return time for transport to day care would benefit carers by enabling them to plan their day more precisely. Transport costs for going on holiday are often prohibitively expensive, and carers would appreciate specific transport schemes or financial assistance.

- Respite care facilities are few in number, offering little choice to the carer or the person cared for. The facilities used were often seen as inappropriate to the person's needs. More choice of respite, both in terms of the number of facilities and in the variety of what is offered, was requested by carers. Provision for people with severe physical disabilities and all younger adults under 65 was a particular cause for concern. Staffing levels which were sufficient to offer personalised care and attention were seen as an essential requirement.

- Carers made similar comments about day care. They were concerned about the limited range and the failure to adapt the service to meet the needs of younger adults. Carers using the Alzheimer's Day Centre in the Peterlee/Seaham area valued it highly and would like to be able to use it five days a week rather than three.

- A specific need was identified for more male sitters to provide male companionship.

- Carers suggested that volunteer help could be used more extensively to improve the quality of daily life for the person cared for and, indirectly, for themselves. Befriending, entertaining, cooking and wheelchair pushing were some of the tasks which they thought volunteers could manage successfully.

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Appendix 1: Summary of Characteristics

Carer

	Gender		Age					Marital Status			
	Male	Female	under 30	30 to 44	45 to 59	60 to 74	75+	Married	Separated / Divorced	Widow/ widower	Single
Focus Group Totals	4	15	1	2	9	6	1	14	1	2	2
Seaham/Peterlee interviews	3	7	0	1	6	3	0	8	1	0	1
Teesdale interviews	0	8	1	3	4	0	0	4	3	0	1
Grand Total	**7**	**30**	**2**	**6**	**19**	**9**	**1**	**26**	**5**	**2**	**4**

Person(s) Cared For

	Relationship							Gender	
	Parent	Grand-parent	Brother/ Sister	Spouse	Son/ Daughter	Partner	Other	Male	Female
Focus Group Totals	4	0	2	12	5	0	3	11	15
Seaham/Peterlee interviews	2	0	1	6	3	0	0	6	6
Teesdale interviews	4	0	0	2	1	0	1	4	4
Grand Total	**10**	**0**	**3**	**20**	**9**	**0**	**4**	**21**	**25**

	Age						Share same household		
	under 18	18 to 30	30 to 44	45 to 59	60 to 74	75+	Yes	No	Sometimes
Focus Group Totals	1	3	4	6	7	5	21	5	0
Seaham/Peterlee interviews	0	1	2	4	2	3	10	2	0
Teesdale interviews	0	1	0	3	1	3	4	4	0
Grand Total	**1**	**5**	**6**	**13**	**10**	**11**	**35**	**11**	**0**

Client Group

	Older People (over 65)	People with physical disabilities	People with HIV/AIDS	People with learning disabilities	People with alcohol and drugs problems	People with mental health problems	Older People with Mental Health problems	Older People with Physical disabilities	Older People with physical disabilities and mental health problems
Focus Group Totals	6	19	0	6	1	5	0	3	0
Seaham/Peterlee interviews	4	11	0	3	0	5	2	4	2
Teesdale interviews	4	7	0	1	0	3	1	4	1
Grand Total	**14**	**37**	**0**	**10**	**1**	**13**	**3**	**11**	**3**