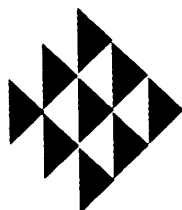




King's Fund



Carers Impact Project in East Sussex

Report on the focus groups and
interviews conducted with carers in
October & November 1997

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Appendix 1: Summary of Characteristics

How the interviewees heard about the Carers Impact study

1 Introduction

1 a) Who we spoke to

48 carers were involved in the project in East Sussex, caring for a total of 54 people. 27 of these carers came to one of three focus groups (in Eastbourne, Heathfield and Hastings), and 21 were interviewed in their own homes.

There was a predominance of female carers in both focus groups and interviews; overall there were 34 women and 14 men. Only 10 carers were less than 45 years old, and 20 were aged 60 or above. All described themselves as White British. They were most likely to be caring for a spouse (23) or a son/daughter (19). Fewer than a quarter (11) were caring for parents or parents-in-law.

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 and highlighting any improvements that could be made to their circumstances. Their replies were recorded on a 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 views on improvements in current services are then presented.

2 What the carers told us

2 a) Caring background

2 a) (i) The person cared for

Of the 54 people cared for, more than half were over 60 years old, and the majority of these were over 75. Most (46) lived in the same household as their carer. They could not be fitted neatly into client group categories since they were often experiencing multiple problems. However, physical disabilities were common in all age groups, and were sometimes associated with learning disabilities among younger people and with mental health problems among the over 65s. Mental health problems were also an aspect of the care of several younger people.

2 a) (ii) Length of time caring

Those who took part in the study had been caring for widely varying periods. The newest carer interviewed was someone whose wife had developed an acute illness two years ago; at the other extreme was a woman who had looked after her son for 34 years.

Several carers described a caring career which had changed significantly over time. Two distinct phases were often discernible - the early stages of illness or dementia during which normality could more or less be maintained with simple adjustments to the daily routine, and a more advanced stage when life had to be organised almost entirely around the needs of the person cared for. Sometimes a crisis, such as an emergency hospital admission, marked the transition between these stages but more often it was the realisation that the person cared for could no longer manage a vital function, such as walking or eating, unaided.

In such situations, people tended to date their self-awareness as carers to the beginning of the more intensive period of caring. In contrast, those who had begun to care following a sudden illness or accident described a more abrupt change in their identity, which for some was also marked by a change in their own lifestyle, such as giving up a job or moving in with an elderly parent.

Parents of children with disabilities were the most ambivalent about their identity as carers. A mother of two small boys with learning disabilities said that she saw herself first and foremost as a parent and was more aware of herself as a carer in relation to her elderly mother. And another parent of a teenage daughter with severe physical and learning disabilities said that she

had only become aware of herself as a carer at the beginning of the teenage years. For both these mothers, the consciousness of providing care which was over and above that associated with normal parenting had gradually dawned as they compared their children's progress with that of siblings or children outside the family. Media references to disability were also mentioned as a trigger for reassessing their role.

2 a) (iii) What caring involved

Almost all of the carers were looking after people who needed assistance with their personal care. Where the person concerned had some mobility and independence, the care was mainly in the nature of assisting with tasks and keeping a watchful eye in case of accidents. But at its heaviest, personal care involved a demanding and rigid routine of washing, feeding, toileting and changing. People with severe mobility problems had to be helped to move between bed, toilet, bath and wheelchair, either by hoisting or lifting, and these manoeuvres had to be repeated several times over the 24 hours. Excursions required careful advance planning, both in order to get the person out of the house and to devise a manageable route for walking or wheelchair-pushing. In several cases, the difficulties were such that the carer had abandoned regular outings.

Disrupted nights were the norm, whatever the level of disability of the person cared for. Those with some mobility required help in order to reach the commode or the toilet while those with more severe disabilities needed frequent attention to relieve physical discomfort.

The constant personal supervision required by people with dementia was a significant additional element of their care and was often experienced as more stressful than the practical tasks. The carers often felt frustrated when the person did not co-operate with the task in hand, or tried to help when it was inappropriate. One carer whose wife needed constant supervision in order to prevent her from wandering commented that he had a 60-second-a-minute job rather than a 24-hour one.

A number of carers included entertaining the person cared for among their caring tasks. One man's wife became rather uncooperative when she was bored; and another felt the need to keep his wife's spirits up in the face of difficult circumstances. Coping with difficult and erratic behaviour was also identified as a central task by a carer who was looking after an adult daughter with mental health problems.

Parents of children with learning disabilities often considered that while the physical care they required was similar to that needed by other children, the needs for supervision and entertainment were greater. One mother of two little boys felt that they needed firmer and more consistent routines than the other children in the family, and this had meant less flexibility and spontaneity

for herself and other members of the family. Another parent with a young Downs Syndrome child described her as "*Lovely but demanding*" and felt that the needs of her other children were often not met because of the extra attention which she required.

2a) (iv) Changing demands over time

The experience of almost all carers was that the demands made upon them had increased over time. Usually this was because the condition of the person cared for had deteriorated so that they could manage fewer and fewer tasks for themselves. For the carers, this meant an increasing burden of both physical care and household management. In some cases, the demands had intensified rather than changed; for example, a parent carer said that while the nature of the help which her daughter needed had remained constant, it was taking longer to provide as she grew bigger and heavier. Making a similar point but in very different circumstances, another carer said that her mother had needed more concentrated attention and support as she grew more frail.

Only one of the carers interviewed considered that caring had become easier; this was the husband of a woman who had been paralysed by a stroke and who had gradually recovered some mobility since her return from hospital. Another carer said that she thought the demands had not changed but she had become less able to cope as she became more tired and more tense.

For the carers of children with learning disabilities, the physical demands of caring had also diminished over time but the sense of responsibility for promoting their development had increased, along with worries about their longer-term future. For three of the carers interviewed and several attending the focus groups, the transition to adult services at the age of 19 had created an immediate and unwelcome increase in demands.

2 a) (v) Help from family and friends

All those interviewed said that they were the main carer (including a parent carer couple who identified themselves as joint main carers), and several identified themselves as the only carer. The involvement of other members of the family and neighbours was usually limited to "popping in" and providing occasional practical help with shopping or household chores. Only two carers received daily "hands on" help with personal care tasks; in both cases, these were parent carers who shared part of the care of their child with members of the immediate family living in the same household.

Two carers had regular arrangements with friends and neighbours for sitting. One of these men had until recently been in full-time work and had organised a rota of informal help for his wife which enabled him to continue until retirement.

Where family and neighbours were regularly in touch, the carers were generally appreciative of the help they were able to give and accepted its limitations. There was a widespread perception, for example, that the more intimate care tasks could not appropriately be shared without compromising the dignity of the person cared for. A few carers did, however, express resentment of their families' lack of interest, and one man commented that caring had taught him that he had many acquaintances but few friends.

2 a) (vi) What got them down

A few carers felt that the whole situation had got them down and were unable to pinpoint specific sources of stress. As one woman said,

"It's everything. It's just been too much for too long"

More often, the carers pointed to one aspect of caring which they had found especially difficult to cope with. For some, the hardest thing was the loss of spontaneity and independence in their own lives; and the consequent combination of feeling socially isolated but having no personal space within the home. This was neatly summed up by a man who said,

"It's not being able to do anything independently. I've no friends and no life of my own. Wherever I go I have to take (my wife)."

The rigidity and sameness of the daily routine got many carers down, and some admitted to frustration with the person cared for. Incontinence, night-time waking and incessant repetition were particular sources of strain. It was not always the caring itself which got them down but rather the lack of support for the caring task, either from family and neighbours or from formal services. Unpredictable and inappropriate services, or services granted and then withdrawn, were seen as a source of extra strain rather than a means of relief:

"What gets me down is the way services don't provide what they promise. When you need them, the services aren't there or don't respond appropriately. They only respond with what they are able to give."

One carer felt very strongly about the injustice of the situation that carers find themselves in. She resented having to pay for services out of a very low income, and having a total lack of status and visibility.

2 a) (vii) What they enjoyed

A few people were unable to enjoy anything about caring and regarded it simply as a job to be done. Most, however, found substantial compensations in their relationship with the person they cared for even if they found aspects of the practical care distasteful or exhausting. One woman enjoyed the company now her husband was at home all the time, and several parent carers said they enjoyed their children. A man who cared for his wife with advanced dementia talked of his pleasure at her reaction whenever she saw him: *"She recognises me and her face lights up"*. Seeing their children take small steps forward was important for the parent carers, and some of those caring for adults also took pleasure in signs of recovery or progress.

Several carers gained satisfaction from knowing that they were doing everything possible to meet the needs of the person they cared for and that they were able to provide them with a better quality of life than they would enjoy in residential care.

2 b) Access and assessment

2 b) (i) Access to services

➔ Pathways to services

When they first began to care, only two of those interviewed had a clear idea of the support which they would need in order to cope. Where illness or disability had struck suddenly, the carers said that they had been unaware at first of the longer-term needs of the person concerned. Others whose caring responsibilities had built up gradually had simply carried on coping with the situation as it developed.

Pathways to services were generally poorly marked, with plenty of false starts and dead ends. Few carers had identified a single source of information or received active professional assistance in analysing their support needs. Instead, support had usually been found through a combination of perseverance and chance. As one woman said,

"Nothing seems to be given to you. It seems that everything I found out about was by luck, delving,"

Another man spoke of the *"lists and lists"* of people he had rung about services to support his wife at home and of the feeling that most had regarded him as stupid or obstinate for refusing to put her in residential care.

Making contact with other carers was frequently seen as a breakthrough point because it provided an overview of services filtered through the practical experience of people in similar circumstances. Whereas professionals focused on one aspect of the situation - usually the condition of the person cared for - other carers had an understanding of the wider issues. But once again, these contacts tended to be accidental, as in the case of a woman who picked up a leaflet about a carers support group while attending a yoga class at her local community centre. It seemed that no-one was assuming responsibility for identifying carers and linking them up with local sources of local support.

Carers who had contacted voluntary associations had generally found them to be good sources of information. The Stroke Association and the Alzheimer's Disease Society were both mentioned in this context. However it had been the carers who took the initiative to find out that the organisations existed and to contact them.

➔ ***Professionals as information sources***

Professionals varied tremendously in their effectiveness as sources of information and support. Three carers reported excellent experiences of prompt and co-ordinated help. In two of these cases, support was organised by hospital staff following an emergency admission for the person cared for. One carer recalled how the head of occupational therapy at the hospital had come to look at her home along with an assessor from Social Services prior to her mother's return. Links were quickly made with Crossroads and with a respite care facility, and the district nurses were also forthcoming with ideas about what might help. For the other carer, a hospital doctor and social worker had played a similar role in ensuring after-care support and the provision of equipment at home. The third carer was a parent who had previously lived in a different part of the country where she had received first-class support from an integrated centre for children with disabilities; sadly, however, this standard of service had not been maintained when she moved to East Sussex where she found provision to be fragmented and difficult to access.

In sharp contrast to these positive experiences, a few carers reported difficult encounters with professionals. One man whose wife had suffered a stroke had found the hospital consultant rude and had had no access to a hospital social worker. When eventually contacted by his local Social Services team, he had been offended by the "bumptious" attitude of the social worker concerned who had rung up to propose, without a face-to-face assessment, that Social Services should send a team to look after his wife during the day but that he would look after her at night. When the carer commented that this division of labour would be quite stressful for him, the social worker offered to "bung in a catheter." Another carer who had rung Social Services to find out about the installation of hand rails felt

that they were immediately on the defensive, saying that they could not do the work and could not fund it. He eventually arranged for the rails to be installed privately through a local builder.

In the middle of the spectrum, were those professionals who had been found to be helpful in their approach but limited in the depth and range of information they were able to provide. The vast majority of GPs fell into this category. Although they were seen as willing to respond to requests for help, they were rarely forthcoming with advice and were generally seen as poor sources of information. Carers felt that their knowledge of the full range of services available was inadequate, particularly in specialist areas such as paediatric care and, besides, they often seemed to be over-stretched and preoccupied. Given that GPs were not providing an effective access point for information and advice, some carers identified the need for another type of professional to take on this role. One suggestion was for a key person, with knowledge of the full range of services and facilities, who could visit carers and talk about the help available. A generic approach to information-giving was seen to be important in order to plug the information gaps between different specialisms.

➔ *Help for themselves*

Many carers identified a need for emotional support but only a small minority of those interviewed had looked beyond family and friendship networks to find it. Six carers had regularly attended carers support groups and one of these had had to give up as her partner's condition worsened and it became more difficult to leave him. The practical difficulties of getting out of the house had proved to be an obstacle for another man who was desperate to meet other carers and was considering forming a loose association of people in similar circumstances who could meet informally in each other's homes. None of the carers had received professional counselling and most did not appear to have considered it. One exception was a parent carer who said that counselling had been an attractive option at an earlier stage when she badly needed support but was reluctant to talk to other parents; however, there had been no time to pursue it. Another carer had gone to see her GP because she was feeling low. The doctor told her that she needed more personal space, but she found this impossible to organise.

For several carers, the Care for the Carers organisation was an important source of "hard" information about matters such as insurance and benefits through its regular newsletter. One carer was active in the organisation and had established a network of friends who were also involved.

2 b) (ii) Social Services Assessments

➔ *The prevalence of assessments*

A majority of the carers interviewed had discussed their needs for help and support with Social Services during the past two years. In almost all cases, the carers spontaneously referred to these discussions as assessments. Several carers reported that more than one assessment had taken place.

Where assessments had *not* been carried out, the carers had either chosen not to involve Social Services (despite being aware of their right to ask for an assessment) or perceived Social Services as marginal to meeting their needs (as in the case of a parent carer for whom Education was the central, co-ordinating point for the support which her children received), or they had had assessments in the past but not recently. An exceptional case was one where two people were being cared for. One had had an integrated assessment, and a package of services offered for both people despite the fact that the other had not been assessed.

➔ *Circumstances of assessments*

In several cases, the assessment had been triggered by a crisis or transition in the circumstances of the person cared for, most usually an emergency admission to hospital; but were also initiated when a young person was moving out of the education system into adult services. Sometimes assessments had followed decisions by carers to seek adjustments to existing support services, such as additional respite care.

The initiative for setting up an assessment usually rested with doctors or hospital social workers where an in-patient stay was involved; otherwise, they were set up by the education services or by social workers following carers' requests for additional services. Two carers reported that they had had to push hard to obtain assessments. One of these regularly took his wife away for the winter months and then faced the problem of having to re-establish services for her on their return to East Sussex. On each occasion this involved a re-assessment of her needs, which took time and added to the existing discontinuities in the services received. The second was a parent carer who had requested a community care package to be set up for her daughter on leaving school and who felt that she had had to chase the key players and co-ordinate the entire process.

➔ *Assessment settings and processes*

In almost all cases, assessments had been undertaken by social workers in the carers' own homes. Where the person cared for had had an in-

patient stay, there had in a few instances been a formal, preliminary assessment in hospital which had involved the carer; more often, however, the hospital social worker had initiated a community-based assessment by alerting the local Social Services team. One carer reported that his wife had been assessed at a specialist hospital unit but that he had refused further contact from Social Services locally because of the offensive attitude of the social worker who had made contact (see earlier).

The assessments had usually taken place in the presence of both the carer and the person cared for. A separate discussion with the carers had occurred only when the other person happened to be out of the home, and had not been explicitly offered as an option. Equally, in most cases, it did not appear that the independent perspective of the person cared for had been sought. In one instance, however, the Social Services Department has appointed an independent advocate for the person cared for, and the advocate was present at the assessment. The advocate subsequently made recommendations which were rejected by the Department. For the other carers, the joint approach was not seen as an issue, although one carer speculated that there might be circumstances in which other carers might wish to discuss issues confidentially.

Although several carers acknowledged differences between their own care preferences and those of the people they cared for - usually the other person wanting less help from outsiders than the carer considered necessary - most of them believed that such issues had been satisfactorily negotiated between them and did not see the assessment process as an arena for reconciling differences. In one instance, however, the assessment did uncover differences which had not previously been acknowledged. Here the carer had held a separate discussion with a social worker about her need for respite care for her husband who suffered from dementia. When she later reported the gist of the discussion to her husband, he had assumed that he was being "put away" and became distressed. Another carer particularly wanted the person she cared for to have some counselling to enable him to acknowledge her needs to accept more services to give her a break.

The carers had to rely on their own recollections for details of what had been agreed in the course of the assessments. While most believed that a written record had been made of the needs of the person cared for, only seven had received a copy and two of these had done so only after making a specific request. One of the latter had then pointed out errors in the written record, only to find that subsequent documentation of her daughter's complex case contained coded abbreviations which were indecipherable to her.

Although most carers felt that their own needs had been taken into account during the assessment, in no case had a separate record of these needs been spontaneously made or offered by the assessor. Four carers

(including a couple) had asked for a separate assessment but none of them had considered the outcome to be satisfactory. The couple were told that the Department did not have to do assessments for carers. One of the other carers had experienced a considerable delay between completing a self-assessment and receiving an acknowledgement that it was now on the file, and had only received a copy after she had asked for one. Another was not convinced that she had indeed received the separate assessment she had asked for. She had not been offered an opportunity to discuss her needs in private, having been told that these would be routinely covered during the discussion, and, moreover, had been informed that no extra money was available for meeting carers' needs.

➡ **Carers' experiences of assessment**

Most carers had positive comments to make about those who had undertaken the assessments. Typically, one said, *"She was very easy to talk to. She was friendly, helpful and supportive, and had a nice personality."* A blend of empathy and professionalism was particularly appreciated by the carers, one of whom said, *"She was very good. She didn't preach. She realised the situation and didn't tell us things we already knew."*

There were, however, some dissenting voices. In particular, one woman who had dealt with a series of different assessors in relation to her daughter's care had doubts about how far they were qualified to deal with complex disabilities and complained about their lack of professionalism in failing to respond to telephone calls or to offer support. Her concerns were echoed in one of the focus groups by another parent carer who commented that the assessors who had come to discuss the needs of her deaf-blind son had possessed none of the necessary communication skills. A third carer commented that while each of the professionals he had encountered was individually helpful, too many people had been involved in assessing his wife at different times, with adverse effects upon clarity of decision-taking and continuity of care.

In general, the carers considered that the assessment process had been useful to them, either because additional services had been added or because they had been given an assurance that further help would be available when the need arose. Peace of mind seemed to be almost as important an outcome as extra help. One carer said that the assessment had helped her to realise that she and her partner were not the only ones with problems, and had felt less isolated as a result.

It did seem, however, that carers in the most complicated and difficult circumstances had obtained the fewest benefits from assessment. Thus the parent carer who had requested a community care assessment for her daughter and who had gone to great pains to research and present the

best care options for her, doubted in the end whether the result had justified the effort involved. She had encountered waiting lists for some services and had been told that the money simply was not available to fund others. The alternatives offered by Social Services were, in her view, designed to fit into the available budget rather than to meet her daughter's needs. Another carer said that the various assessment procedures he had encountered had simply reinforced his feeling that only he could care for his wife because her needs seemed to lie outside the scope of available community services. For example, during a lifting trial at a day centre, he had been told that his method of moving his wife from her wheelchair to the toilet could not be used by the staff because it would contravene health and safety regulations. The result was that he was left without day care support. The couple caring for two highly dependent people had had their social care package withdrawn.

Once a care package had been agreed following an assessment, it sometimes proved difficult for carers to adjust it to meet changing needs and circumstances, particularly where extra resources were required. One carer encountered resistance when she asked for extra help with bathing her mother after a series of falls and also for additional sitting to allow her the occasional night and evening off. She was told that these needs could be met only by reducing elements within the existing package. It therefore seemed to her that subsequent assessments were geared primarily towards containing growing needs within the original funding allocation. Other carers talked of fighting against an erosion of services when the needs of the person they cared for were re-assessed.

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.

Some of the people cared for had complex packages of care. For example, one highly dependent man had district nursing services daily, day care at a hospice twice a week, and helpers organised through the Crossroads voluntary agency. A similarly complicated network of services was supporting an older woman and her carer, involving separate homecare agencies funded by Health and Social Services, regular sitting by Crossroads, and two weeks' respite out of every eight at a residential home, plus domiciliary visits from a chiropodist, a physiotherapist and an occupational therapist when required. But these examples were somewhat unusual. Most people receiving formal services had rather less intensive support - typically an element of homecare

and items of equipment in the home, sometimes complemented by day care or respite care.

School (mainstream and special) played a vital part in the lives of the children with learning and/or physical disabilities. Two small boys with severe language disorders and mild autism attended special language units, one of which was located within a mainstream school, and an older girl with complex disabilities attended a Further Education Department at a Special School. Chailey Heritage School and the Royal School for the Blind in Margate came in for voluble praise from carers attending focus groups. However, day care for adults with disabilities was more patchy. Among those interviewed, only a third of the adults cared for attended day care and then for only one or two days per week. One person attended two different day centres, one in a hospital and one run by the Social Services Department.

A notable feature of the situations described by the interviewees was the number of people receiving minimal services or none at all. A quarter of the adults being cared for were receiving no statutory services. They managed with small amounts of privately paid nursing care or speech therapy, and informal sitting arrangements, or relied entirely upon the carer.

Within the interview group, residential respite care was being provided for only five of those cared for. In one of these cases, the original admission for short-term respite had become a semi-permanent arrangement. In three further cases, respite arrangements were in place but had not yet been used. Two adults had respite at home (one of which was organised independently), and one of the children had a link person for respite outside the home for a few hours. Among the carers attending focus groups it was clear that some of the people cared for did receive residential respite care; and some were permanently in residential care.

Social work services were a background presence in the lives of most carers, but this was usually for routine matters like organising respite care, or adjusting components of the existing package.

2 c) (ii) The right level of support

The carers interviewed were asked whether they thought they had the right level of support to help them care. A slight majority of the carers said that they did, although this was qualified in some cases. One man said "*for the moment, just...*" and several felt that while the services they already received were valuable, they would benefit from these being extended and, in some cases, from additional support being added. One woman, for example, said that she would like her husband to attend his day centre for an extra day in order to give her more time to attend to household tasks, and she also wanted some kind of regular support in the home which would enable her to go out during the evening or at weekends.

Among those who did *not* consider that they had the right level of help, emotional support, flexible sitting services and adequate provision outside the home through day care or respite care were identified as the main unmet requirements. Two carers (a couple) were very unhappy about the absence of any services. They had had six packages of care agreed and subsequently withdrawn within the past two years, and were waiting for the current package to be implemented.

The carers interviewed gave the impression of having low expectations of services and high expectations of themselves and the necessity of coping with the level of service they already had, or of making their own arrangements if they felt there was a shortfall.

2 c) (iii) Choice

Carers were asked questions in the interviews about how much choice they and the person cared for had been able to exercise over the help they received. Most did not consider that they had been given a menu of services to choose from. At best they had been offered a particular service which they had decided to accept or, more occasionally, to refuse. Often too, the amount of service was already prescribed - for example, two hours' sitting on a Wednesday afternoon.

The dominant experience was, therefore, of being told what they could have rather than of exercising real choice. This did not necessarily matter to them so long as what they did get was of good quality and appropriate to the needs of the person cared for. But some undoubtedly would have liked more choice and also more professional support in making that choice. One woman summed up this feeling by saying,

"I've just picked and chosen what I've thought suitable. I've had no support from any named person. Community care is supposed to be about choices but I don't think we've been offered any choices".

A closely linked issue for some carers was a lack of choice over how services were delivered. As another carer commented,

"The help I get would be reasonable if I could have it when I want it and how."

Some carers had exercised choice by making their own arrangements paid for privately by themselves, or through their own informal networks of friends and volunteers. One of them said: *"You have more control over your own life while you manage independently and organise things yourself"*. Another carer

who did not have the funds to make these choices wished that she did because *"it would be better for your own privacy"*.

Only one of the carers interviewed had been offered a choice initially between alternative service providers. In this case, she had been offered a list of approved nursing homes which could offer respite care for her mother. Otherwise providers had been nominated by Health or Social Services. A few people had exercised choice at a later stage, as in the case of two carers who had been dissatisfied with private agencies providing homecare services and had been able to change providers. Another carer was considering using a different residential respite facility for her mother and had been offered a list of alternatives. In most cases, the carers accepted that options were limited and were satisfied with the providers they were offered.

Most of the people cared for were seen not to have had a choice over their services, partly because of the lack of options open to them, and often, additionally, because their mental health or physical capacities did not enable them to make, or express choices. However, the carers insisted that welfare of the person cared for was always central to the decisions about the services they received and if there was a tension between their wishes and those of the carer, this was resolved by compromise. They believed that they were sensitive to the moods of the people they cared for and could tell whether or not they were contented with their experience of services, even where the person cared for had no speech.

2 c) (iv) Current problems with services

Services were vital to the coping strategies of most carers, attracting many expressions of appreciation and praise. Where problems arose with services, however, they added to the caring workload and were an additional source of strain. Problems covered a wide spectrum from the carer whose only comment was that she would like her cleaner (whom she paid herself) to come earlier, to a family with a history covering several years of negotiation to obtain a level and quality of service provision that was mutually acceptable to the carers and Social Services Department - a process that was still unresolved.

➡ **Quality and flexibility of agency homecare services**

Some carers had experienced problems with agency homecare services. The problems had covered poor time keeping, constant changes of personnel, training, and reliability. One carer had solved the problem by dispensing with the help altogether, and two others had changed agencies. There were complaints about the service arriving at unpredictable times, often inconveniently early in the morning or late in the evening. One carer did not have help at bed times because the service

could not be provided late enough to meet their needs, and she preferred to have their evenings together than to have help to put her husband to bed.

➔ *Flexibility of day care*

On the whole carers appreciated the day care services that they received. However, several carers would have liked more flexibility in the hours provided and/or more predictable times for the collection and return home of the person cared for. The combination of a short day and erratic transport reduced the benefit of the service for the carer. One woman would have liked to take a part-time job but found that this was impossible with the current hours available. Another chose to pick her husband up at 4.00 pm at the end of the day, rather than rely on the day centre transport which might arrive as early as 3.15 pm.

➔ *Day care of appropriate type and quality*

The carers of older people were generally satisfied that the day care they received was appropriate to their needs. Among those caring for younger people with physical disabilities, however, there were concerns about both the facilities and the quality of care provided. For example, one carer felt that her son's physical care was poorly managed, particularly his toileting needs; there was only one day centre that he could attend and because it did not have appropriate facilities, he had to take his toilet with him on the bus. Another complained that her son's clothing frequently went astray. She had tried to institute a resource book at his day centre but the system lapsed whenever his key worker changed. There were several complaints about a lack of feed-back from the day care facility about the person's behaviour and well-being.

➔ *Residential respite*

Several carers relied upon regular residential respite and were fully satisfied with the quality of care. Where problems had arisen, however, they undermined the carers' trust and made them less likely to use the service in the future. Examples of poor care included a child returning from respite with unexplained bumps and bruises, several people contracting urine infections, and one man absconding whenever he had been placed in residential care, indicating poor supervision. A carer whose wife suffered with Alzheimer's had been so upset by the bizarre and unrestrained behaviour of people attending a respite facility when they had gone for a preliminary visit that he had refused to consider any form of residential respite for his wife, at considerable cost to himself.

➔ ***Access to services***

One family had experienced problems with accessing and keeping services. They felt that the professionals in the Social Services Department were hard to contact, did not return phone calls or letters, and had on one occasion said that the people cared for were a drain on society. The family had used the Department's complaints procedure, but had felt that their treatment was worse as a result. This family said that they had had six packages of care agreed and withdrawn from them within two years.

➔ ***Resources***

The lack of money for services, and the threat of cuts to existing provision was a theme throughout the focus groups and interviews. Carers were often cautious about asking for services, and wary that what they were given would be withdrawn. Some carers were using less residential respite than a year ago because of reductions in funding from Social Services, and one carer said that it was hardly worth applying for residential respite because places in the only suitable facility for his wife would be gone by the time his request had gone before the funding panel. For some services, marginal extra amounts of funding would have resolved difficulties and given added value for both the carer and the person cared for. In one case, a problem had arisen for a carer whose son was taken by the sitter to a club, but the expenses would not cover the petrol costs.

➔ ***Appropriate provision for the hearing impaired***

Provision for people with hearing impairments was seen as inadequate in both education and day care provision; particularly where the person cared for had other disabilities, the carers felt that the hearing impairment was overlooked.

➔ ***Physiotherapy services***

A number of carers in the interviews and focus groups commented on the lack of physiotherapy services. Where the person cared for had had physiotherapy, the carers often wanted it to continue beyond the time allocated, and to be extended to be available in the home, and in day centres.

➔ **Access to health care in Social Services facilities**

The lack of input from Health into day care and residential respite facilities was identified as an issue. Unmet needs included physiotherapy (see previous point) and nursing care. One man related how his wife had become severely constipated while in residential respite. The care workers were not qualified to give her an enema and they were unable to call upon nursing staff at a linked Health facility on the same site. He was told that the procedure could only be done by the district nurse when she returned home. Parent carers who were accustomed to access to paediatric health care worried about whether their child's health needs would be met appropriately when they entered adult services. For this reason, one woman had reached an informal understanding with her daughter's paediatrician that she would continue to see her when she left school.

2 c) (v) Help from the GP

Most carers found their GPs helpful within limits. The GPs varied considerably in their acknowledgement of the carer's needs. Only one offered regular contact and support (by giving the carer a chance to come and have a chat every fortnight) but most would respond to requests for visits, and refer to a hospital consultant if the carer was worried. Getting access to their regular GP for an emergency appointment was reported to be a problem by several carers, and this diminished the continuity of care. Two of the carers interviewed had decided to change GPs because they had felt poorly supported. The comments from the other carers varied from those who were very positive about the help they had received to more lukewarm responses.

As noted earlier, GPs were not considered to be good sources of information. Usually, they would answer questions if asked but did not volunteer information and were not thought to be well informed about services.

A new development noted by one carer was the appointment of a carers worker to her GP's surgery. Although this was too recent to have benefited her directly, she anticipated that this would add significantly to the support available for carers.

2 c) (vi) Liaison between services

Liaison between services was not a relevant issue for almost half the carers interviewed because they were either receiving only one service, or none at all apart from their own informal arrangements.

Among the remainder, there was a general belief that liaison was poor, usually because the different services made no reference to each other or because an obvious failure of communication had arisen. One carer referred

to the different agencies as "*separate entities*" and recalled that when the services of a bath nurse were withdrawn by Health there was no handover to Social Services, leaving him try to re-establish the service. The same carer had an agreement whereby Social Services would service his wife's wheelchair but, since this had never happened, simply did it himself. Often carers saw themselves as the only point of liaison between services:

"No, there's no liaison at all. They're all acting independently. If there's a hiccup with one, I have to phone around and fix it."

Only two examples of good liaison were given. One involved termly, multi-disciplinary reviews for a child who attended a special school. In the other case, the carer reported that there had been excellent communication between the primary health care team, hospital services and Social Services before and immediately after her mother's return home from hospital and a convalescent nursing home.

2 c) (vii) The Impact of Services

The carers interviewed were asked questions about the impact of services. Specifically, they were asked whether the services they received gave them more time for themselves; how far they made a difference to the person cared for, and whether they had an impact upon their relationship.

From their answers it is clear that services can have a valuable impact on the lives of carers by providing regular relief from the demands of the caring routine. The time off provided through day care and respite was particularly important since it offered a complete break. This was not necessarily seen as time for themselves, however, since carers often spent it simply catching up on routine chores and family business which could not be accomplished in the presence of the person cared for. Parent carers would usually take the opportunity to spend time with their other children. A few carers did manage to use their time away from caring to expand their own horizons: to work, albeit part-time; take evening classes; decorate; and, as one carer put it "*to mess around.*"

Some of those interviewed considered that the services they received released no time for themselves. This was usually because the person they cared for was not attending facilities outside the home, or because the amount of external care was limited. There were instances where carers felt that their presence was necessary to assist inexperienced homecare staff with bathing and lifting, leaving less time for themselves. Where sitting was provided, it was not always arranged so as to maximise the benefit to the carer. For example, a woman who had formerly received a whole day's sitting found the service much less satisfactory in meeting her own needs when it was altered to two afternoons. In general, inadequate or fragmented support

left carers feeling hurried and frustrated and seemed to add to rather than relieve the stresses of caring.

When asked about the difference that services made to those they cared for, several said that the person concerned put up with the involvement of outsiders as a necessary but regrettable option. Nonetheless, most carers believed that services had a positive impact, emphasising in particular 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. Regular sitters and, in some cases, homecare workers also made a difference to the people cared for. In some cases they had become friends of the family, and the visits were anticipated with pleasure. They provided social contact and friendship as well as relief care.

Some carers had difficulty in deciding whether the services they received made a difference to their relationship with the person they cared for. Many, however, were able to identify benefits from spending time apart and sharing an element of the care. Being more patient and relaxed, and having new things to talk about together were particularly important. One parent carer was full of praise for the support her autistic child received. They had enabled him to start forming relationships, he had learned to kiss, and to call her "Mummy".

3 Key Messages

The table below sets out the things that carers want for their lives, their desired outcomes. The information is gained from the interviews and focus group discussions and is presented as statements taken in note form from the interview schedules and focus group notes. The statements do not represent the views of all carers, but were expressed by individual carers during the research.

3 a) 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
<i>Good communication between carers and services</i>	<p>Carers shouldn't be emotionally blackmailed.</p> <p>Carers needs not being taken into account despite being written down.</p> <p>Professional people won't listen.</p> <p>People tend to think you're thick because you've got a child with learning disabilities.</p> <p>Professionals not forthcoming with information.</p> <p>Carers regarded as nothing.</p> <p>Hospital consultants only see you for 5 minutes.</p>	<p>Being told the full price of services that carers will have to pay.</p> <p>SSD taking the initiative to contact the carer.</p> <p>A more positive approach.</p> <p>Assessors to have good communication skills.</p> <p>Someone to sit down and explain information at the beginning.</p>
<i>Easy access to services</i>	<p>Social Services Department making excuses which we know are not true.</p>	<p>Agreement and funding for appropriate placements even if they are out of county.</p>

Desired Outcome	Factors which hinder	Factors which help
<i>Easy access to services (cont.)</i>	<p>Funding shortages leading to cuts in services.</p> <p>Unrealistic assessment of needs by SSD.</p> <p>Solving problems/form filling and phone calls are very time consuming.</p> <p>You ask for something and you're told there's no money.</p> <p>You have to fight for everything.</p> <p>Constant battle against erosion of services.</p>	<p>Hospital to recommend and supply equipment.</p> <p>Assessments should be needs led not resources led.</p> <p>Help from voluntary societies/ associations.</p> <p>Practical help as well as advice.</p>
<i>Help in an emergency</i>	<p>The whole thing falls apart if the carer sprains her ankle.</p>	
<i>Emotional support</i>	<p>Groups of carers make you feel depressed.</p> <p>Neighbours saying they don't want your sort.</p> <p>Other members of the family assume you will care.</p> <p>People are afraid of disability, social circle diminishes.</p>	<p>Help from family members.</p> <p>Help to build up confidence.</p> <p>Guidance and counselling.</p> <p>Somebody to talk to.</p>
<i>Having a life of your own</i>	<p>Carers guilt about asking for help.</p> <p>Carers need to feel indispensable.</p> <p>Carer not able to bear person going into residential care.</p>	<p>Time to be with siblings of disabled child.</p> <p>Carers need their own life.</p> <p>It is important for carers to get out of the house.</p> <p>Independence for the person cared for.</p> <p>Family involvement so that the carer can have a social life.</p>

Desired Outcome	Factors which hinder	Factors which help
<i>Having a life of your own (cont.)</i>		Regular activity/evening class for the carer. Sometimes residential care is better than insanity for the carer.
<i>Time off</i>	Poor quality respite care. People cared for reluctant to accept help.	Initiate respite early on and build up slowly. Carer having confidence in care services. Freedom to be with the rest of the family. Carers need time off to rest at home.
<i>A decent income</i>	Carers' benefits are too low, and are taxable. Not able to take a part-time job because care available only for a small number of hours. Unable to get a mortgage. Having to pay to hire necessary equipment. Buying equipment is expensive. Carers lose income when the child becomes an adult. Having to give up work to care. Being given wrong information about benefits. Large part of salary devoted to care costs.	Advice about employment and benefits. Professional care team/ services organised around carers need to work.

Desired Outcome	Factors which hinder	Factors which help
<i>Reliable and appropriate services of acceptable quality</i>	<p>Paid carers can't lift on their own.</p> <p>It is difficult to achieve the right quality of care in respite.</p> <p>Uncertainty about when equipment will be available.</p> <p>Problems with feeding patients in hospital.</p> <p>Day centre services can't provide for the needs of people with multiple disabilities.</p> <p>Lack of services for people with disabilities aged over 19.</p> <p>Paid carers not trained to deal with incontinence.</p> <p>Staff in hospital have no basic training in Alzheimer's disease - don't understand the need for constant supervision.</p> <p>Constant changes of personnel.</p> <p>Lack of care from GP.</p>	<p>Respite care at home, with the same carers, qualified and experienced.</p> <p>Purpose built homes for disabled people.</p> <p>Physiotherapy and occupational therapy at home.</p> <p>Appropriate day care with all the essential equipment.</p> <p>Preventive care services would save money in the long-term.</p> <p>Sitters trained in lifting.</p> <p>Provision which sees the whole person.</p> <p>The dignity of the person cared for is important.</p>



2 b) Carers views on improvements needed in East Sussex

➡ *Information and support*

Carers expressed a need for information and personal support to assist them in making decisions and choices, particularly in the early stages of caring and at points of transition, such as the end of schooling or admission to residential care. Where the need for care stemmed from an acute medical condition or birth defect, they stressed the importance of knowing the diagnosis and of having someone talk through all the implications with them. Their experience was often less than ideal, leaving them feeling in the dark and at a loss where to turn.

It was felt that much more information should be available about what kinds of assistance were available, and who to approach to obtain help. Carers had anxieties about knowing where to get help as the needs of the person they cared for increased. One suggestion was that a multi-agency advisor should be appointed who could provide carers with personal guidance about available care options as the caring situation unfolded. Better signposting of new carers to carers groups and carers courses was also requested, and some isolated carers who were effectively housebound wanted opportunities to contact carers in similar situations.

➡ *Assessment process*

Carers had several suggestions for improving the assessment process. Those in complex situations which involved an input from several services wanted more efficient co-ordination of information and a streamlining of assessment meetings, with fewer individuals involved but greater continuity between them. A case was put for an independent advocate for parent carers, perhaps provided by a separate agency, to help them negotiate their child's transition from the education system into adult services. Parent carers also wanted more effort to be put into advance planning of their child's community care needs, with more contact at an earlier stage between schools and Social Services assessors, and greater specialist input where necessary.

More generally, carers wanted to see an assessment system which was genuinely needs-led. They felt that too many options were being dismissed because resources were assumed to be unavailable. Better linkage with other sources of funding, such as the Independent Living Fund, was identified as a means of increasing the range of care choices.

A stronger emphasis within the assessment process upon the needs of the carer was another frequent request. Too often these were sidelined or not explicitly considered at all. There was also a demand for unmet needs

to be logged and for more consistent feed-back on agreed courses of action.

➡ ***Homecare Services***

Some carers just wanted more help in the home, but several needed the service to be available for night-time and week-end care.

Carers would like to see more consistency in the experience and training of homecare staff, and they expressed concern that low wages and unsympathetic working conditions (such as unpaid travelling time between assignments) served to depress the overall quality of staff and increase turnover. Continuity of homecare staff was important to the carer and to the person cared for.

Carers also wanted homecare to be delivered at predictable and appropriate times.

➡ ***Social Work Services***

Carers wanted to work in partnership with social workers, and to have good relationships of mutual respect. They considered that they would benefit from more regular contact and support, and believed that the initiative should be taken more often by the social worker.

They felt that carers should be given a stronger voice in care decisions and should be listened to more carefully. Greater continuity of social work personnel was needed in order to promote partnership and trust. Being able to relate to a consistent person who understood their own needs and those of the person cared for, and how those needs changed over time, was considered important.

➡ ***Day care/Respite care***

Carers looked for improvements in the quality of the care already being provided. They wanted staff to pay attention to the small details of caring that made a difference to the people cared for, especially when they could not communicate their own needs. Attitudes of staff and the quality of their training were felt to be particularly important in delivering appropriate care.

Carers wanted day and respite care to be tailored more closely to the needs of the people attending. The needs of younger people with disabilities was brought up a number of times, with a wider variety of provision and greater use of volunteers for activities suggested, together

with appropriate facilities and trained staff. They also identified a need for more day care for people suffering from mental illness.

➔ ***Emergency services and flexibility***

Most carers worried about what would happen if their capacity to care was interrupted by illness or any other emergency. Having some reliable cover in a crisis was considered essential. A helpline for requesting services at short notice was suggested. At the same time, it was seen as important that people coming into the home to take over the caring role in a crisis were known and trusted by the person cared for.

The need for help at short notice did not relate just to emergencies. Carers wanted to be allowed the flexibility to alter a regular pattern of services if the need arose; for example, to look after one child while another had a hospital appointment or to change an evening sitting arrangement in order to go to the theatre.

➔ ***Hospital in-patient facilities***

The carers identified a lack of specialist facilities for people with disabilities when they had in-patient treatment. One suggestion was for a room with proper equipment, such as a hoist, for people with severe disabilities, with space for the carer to stay. People suffering from Alzheimer's disease were felt to need a special unit with appropriate levels of supervision and personal care.

➔ ***Training***

Carers made comments about the training needs of staff in social care and health care roles. Specifically, they would like to see a greater understanding of the needs of people with disabilities, better training for assessments and specialist training on Alzheimer's disease. In order to provide a better guarantee of the quality of personal care services, some felt that paid caring should be treated as a profession with minimum training standards and qualifications.

➔ ***Equipment***

Carers wanted more comprehensive information about equipment to help people with disabilities. Shorter waiting times for deliveries and a less bureaucratic procedure for applying for large items were further requests. Where equipment could not be supplied free of charge, carers looked for affordable leasing arrangements.

More accurate matching between the needs of the person cared for and the specifications of the equipment was called for. Waiting for a major piece of equipment, such as a wheelchair, and then finding that it was not useable caused acute frustration. Also, carers wanted to see a more efficient system for returning equipment which they no longer used so that it could be made available to other people. They resented being told that there was no money to pay for a particular item which they needed when they were storing unwanted equipment which had not been recalled.

➔ ***Funding for services***

Many carers expressed anger at being told that a needed service was not available because of a lack of funding. If they persisted, they felt greedy and demanding and if they did not, they worried that they had not fought for the best interests of those they cared for. They resented being made to feel responsible for agencies' funding problems and they disliked having to compete for resources with other needy people. They wanted a more open and positive response to service requests and a recognition that meeting such requests was a considerably less costly option than providing full-time residential care.

Anxieties were expressed about the possibility of cuts in services and the erosion of their own packages of care over time. They wanted to be able to rely on continuous support for as long as it was needed. Respite link families, Crossroads, and carers networks were seen as particularly vulnerable to cuts and carers were keen to see these services safeguarded.

➔ ***Tighter regulation***

Carers made some comments on aspects of services which they believed would benefit from tighter regulation. These included the vetting of carers in privately run provider services, minimum standards for packages of care to be monitored and supervised, and disabled access for public meetings.

➔ ***Relationship between health and social services***

Carers felt that Social Services should be more assertive in its dealings with Health in order to ensure a stronger health care presence in Social Services facilities and greater continuity of health care in the home. Physiotherapy which was provided in insufficient amounts and for too short a time was a particular source of concern. Parent carers whose children had benefited from a co-ordinated health and education service wanted specific attention to be paid to their health care needs post-19.

➔ **Money/Benefits**

A major theme in the carers comments about improvements was their own need for a higher income. The straitened circumstances of caring meant that they were not able to lead a varied life or to take an active part in community activities. They wanted benefit levels for carers to be higher to reflect their commitment and benefits for people with disabilities to be made more easily accessible.

Although they recognised that these issues lay outside the remit of local health and social services, they felt that more flexible and generous approach to service provision would ease their situation. For example, better support could be provided to enable them to take up employment and training opportunities or to achieve a better mix between existing employment and caring responsibilities. One suggestion for increasing flexibility of provision was to allow carers to purchase an agreed allocation of care services independently; through this means, carers would be in a stronger position to specify their care requirements and would not be restricted to services supplied through a specific purchaser.

Local services were also seen to have a role in improving carers' knowledge of financial benefits through written information and personal guidance.

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	Widow/ widower	Divorced	Single
Focus Group totals	6	21	0	7	8	9	3	23	0	2	1	1
Interview totals	8	13	0	3	9	5	4	14	1	0	3	3
GRAND TOTAL	14	34	0	10	17	14	7	37	1	2	4	4

Person(s) Cared For

	Relationship to carer						Gender		Age					
	Parent	Spouse	Son/ Daughter	Partner	Parents - in -law	Step- children	Male	Female	under 18	18 to 30	30 to 44	45 to 59	60 to 74	75+
Focus Group totals	4	13	10	0	3	0	20	10	5	3	2	3	5	12
Interview totals	4	10	9	1	0	2	10	14	6	2	1	1	6	8
GRAND TOTAL	8	23	19	1	3	2	30	24	11	5	3	4	11	20

	Share same Household			Client Group								
	Yes	No	Some-times	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 mental health problems and physical disabilities
Focus Group totals	25	4	1	17	20	0	6	0	7	6	9	1
Interview totals	21	3	0	11	18	0	9	0	6	6	8	4
GRAND TOTAL	46	7	1	28	38	0	15	0	13	12	17	5

How the interviewees heard about the Carers Impact study

Source	Number of carers
Crossroads	3
GP carers worker	1
Care for the Carers	15 (inc. a couple)
Local carers group	1
Alzheimer's Disease Society	1

King's Fund



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