King's Fund

Carers Impact Project in Bolton

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

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1 Introduction

1 a) Who we spoke to

51 carers were involved in the project in Bolton, caring for a total of 53 people. 31 of these carers came to one of three focus groups (one in Horwich and two in the centre of Bolton), and 20 were interviewed in their own homes.

There was a predominance of female carers in both the focus groups and the interviews; overall there were 43 women and 8 men. Only 6 carers were less than 45 years old, and 22 were aged 60 or above. The overwhelming majority described themselves as White British, with just three carers falling into different ethnic groupings (respectively, Asian/Indian, Asian/British and Pakistani). They were most likely to be caring for a spouse (21) or a parent (17). One was caring for a sibling, and four for people unrelated to them.

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 Bolton, 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 desired outcomes and the factors in their situations which help or prevent these being achieved.

2 What the carers told us

2 a) Caring background

2 a) (i) The person cared for

Of the 53 people cared for, more than two-thirds were over 60 years old, and most of these were over 75. Most (33) 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 mental health problems were also prevalent (affecting 24 younger people and 10 people over 65 years). There were four people with learning disabilities.

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 husband had been discharged from a rehabilitation unit at the beginning of this year following a stroke which had led to dementia. She had suddenly been launched into a demanding, full-time caring role. At the other extreme was a mother of a 36 year old man with learning disabilities who had looked after him since birth.

Most carers, however, 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. Where there was a greater degree of stability and continuity in the relationship - for example, where the people cared for had physical or learning disabilities but no chronic illness - the label of carer was not always recognised or accepted. *"I still see myself as a parent and I still treat him as a child",* said one carer of an adult son, while another woman looking after her disabled sister said, *"I've never actually classified myself as a carer."*

Local publicity about carers services prompted a few people to recognise their role; thus, one woman began to see herself as a carer when she picked up a bookmark in the library about the carers support group.

2 a) (iii) Nature of the care needed

Predictably, there were substantial differences in the amount and nature of the care needed. Older people with dementia and younger people with acute illnesses and physical disabilities required help with many aspects of personal care. At its heaviest, this involved a demanding and rigid routine of washing, feeding, toileting and changing throughout the day, with frequent interruptions at night. 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 wheelchair-pushing. Where the person cared for had some mobility and independence, the practical care was more in the nature of assisting with tasks and keeping a watchful eye in case of accidents.

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. There was also the frustration involved when the person did not co-operate with the task in hand, or tried to help when it was inappropriate. One woman looked after her husband who suffered from a progressive neurological illness. He sometimes tried to help her by getting out of bed or out of a chair himself but ended up falling.

The needs of people with learning disabilities were different in that they could usually cope with their own personal care and with some household tasks. Nonetheless, they needed reminders about each task and about managing their daily routine. Companionship and entertainment, encouragement and emotional support were other important ingredients of their care.

People with mental health problems sometimes had to be helped with their personal care, for example where depression had led to self neglect. More often, care involved supervision of their medication, help with household chores and finances, monitoring their condition and emotional support, sometimes with considerable anxiety on the part of the carer. Two of these carers had experienced violent attacks from the person they cared for when they were in an acute episode of illness.

One of the Asian carers added translating at the doctor's surgery and hospital appointments to her other caring tasks.

2 a) (iv) Changing demands over time

The experience of most carers was that the demands made upon them had increased over time. Usually this was because of a worsening in the condition of the person cared for but sometimes it reflected a deterioration in the carer's own health and capacity to care. Also, several carers had acquired caring responsibilities for elderly relatives alongside their main caring commitment. One woman in this predicament commented that she seemed to have been assigned the role of the family carer, to be called upon whenever support was needed. The conflicting demands which this created were a source of increasing stress.

A few carers commented that the demands of caring had changed rather than increased over time. Parents of people with learning disabilities, for example, said that while the physical demands of caring had lessened since infancy and childhood, they had been replaced by the responsibility for co-ordinating the different support and educational services which the person needed as an adult. Increasing independence for the person cared for could also bring increased worry for the carer. Thus one woman whose son could manage to travel alone on public transport suffered agonies of anxiety when he failed to return home on time.

People caring for adults with mental health problems described a pattern of demands which was unpredictable and episodic in nature. Although the caring was not constant, the carers' experience was of increasing pressure and responsibility for managing the situation. One woman caring for her husband said that she had had seven years of unadulterated hell before he would accept any medication. The demands on her depended on the efficacy of his medication and his willingness to take it.

2 a) (v) Help from family and friends

All but one of those interviewed said that they were the main carer, and several identified themselves as the only carer. The involvement of members of the family and neighbours was usually limited to "popping in" and providing occasional practical help with shopping or household chores. Only one carer received daily "hands on" help with personal care tasks. This was someone whose adult daughters still lived at home or nearby and who were able to provide both moral support and practical help in looking after her husband. Another carer had been looking after her mother-in-law who was currently in hospital after suffering a stroke. Other members of the family were planning to look after the patient when she was discharged.

Carers who were not supported expressed frustration and resentment at their isolation, especially when family members lived near enough to be able to help. Occasionally, however, a deliberate decision had been made not to involve the family unduly, most notably in the case of a carer and his wife who had 6 children and 26 foster children but who were keen to maintain their own and their children's independence.

2 a) (vi) What got them down

The loss of freedom and spontaneity in their own lives was a frequent source of regret for the carers, a feeling well expressed by one woman who said:

> *"It's constantly not being able to do what you want when you want to. Not being able to get up and have your meals when you want to. Having to be organised before going anywhere. It's like having a child but one with her own views."*

Several carers had given up work when the demands of caring had become too onerous and, although they did not necessarily miss the job itself, were conscious of having lost the companionship of their workmates. Even contacts with family members became difficult to arrange, one woman commenting that it was no longer possible just to ring up her sister and suggest going out for a pub lunch.

The loss of the carers sense of self was very real. One carer said:

> *"Sometimes you have to fight for your personality. You have to fight to say I'm me."*

One of the younger carers interviewed had a strong sense of lost personal opportunity. She by no means regretted her decision to care for her sister but realised only some time later that she had missed out on her own education in order to do so.

The rigidity and sameness of the daily routine got many carers down, and some admitted to frustration with the person cared for. Incontinence and repetitive behaviour were particular sources of strain. Knowing that the person concerned could not help their behaviour did not necessarily make it easier to accept emotionally, although it undoubtedly increased carers' guilt when they lost their temper. One carer said that sometimes she felt that she wanted to go to bed for a week and lock the door, while at other times she felt like running away, only there was nowhere to run to.

Several carers said that awkwardness and lack of co-operation on the part of the person they cared for got them down. Usually this involved stubbornness and a refusal to listen but a few carers had suffered physical violence.

Sometimes the inadequacy of services was the principal source of irritation. Difficulties in getting hold of incontinence supplies and frustration at things not being done properly by people coming into the home were specifically mentioned.

2 a) (vii) What they enjoyed

A few people were unable to enjoy anything about caring and felt locked into a predicament which they hated. Most, however, were able to draw satisfaction from the relationship with the person they cared for even if they found aspects of the practical care distasteful or exhausting. Thus one woman said, *"I resent his illness but not him".*

A sense of doing their duty was important to several carers. This might involve reciprocating for the care which a parent had given at an earlier stage of life or caring for a spouse in the knowledge that their roles might have been reversed if life had worked out differently:

> *"If I was in the same situation, she would have done the same for me. I've got a clear conscience. For better, for worse."*

Several carers reported how their sense of humour, and shared laughter with the person they cared for lightened their experience. One woman who cared for her husband who had advanced dementia and had no speech, said that she liked it when she made him laugh.

2 b) Access and assessment

2 b) (i) Access to services

➧ *Knowledge about services*

When they first began to care, very few people had a clear idea of the support which they would need in order to cope. Their ignorance of services made it difficult for them to identify and ask for help, and professional workers were rarely forthcoming with advice or information. *"If you don't ask, nobody tells you",* was a frequent refrain within both the focus groups and the interviews. The carers that did know what support they might need had specialist knowledge through their professional life, or through previous caring responsibilities.

In several cases, long periods elapsed before some services were put in place, even where a hospital admission or an unequivocal diagnosis should have signalled the need for extra support. One man remembered his surprise and disappointment when his wife was discharged into his care following a stroke without any advice being given about how to lift or wash her. Worse still, the services seemed to tail off once she was home, so that, for example, the physiotherapy which she had received in the hospital was reduced to once a week and then once a month at home.

Someone else who had cared for her son with learning disabilities (now in his thirties) since birth, remembered no advice being given at all at the point of diagnosis; indeed the support of a social worker had been available only in recent years, and then only sporadically.

➡ *Who they turned to*

It was rare for carers to find a single source of information to help them meet their support needs. A gradual accumulation of knowledge from contacts with professional staff and encounters with other carers was the more usual pattern. Several different lines of enquiry might be pursued at different times and important information was also happened upon by chance. Access to services was thus neither systematic nor co-ordinated.

The GP was the first point of contact for most people when they first began to care. Social workers also featured as early contacts where the person cared for had been admitted to hospital. Most carers described their first contacts as useful but as offering only partial information. An exception was a carer who had received comprehensive advice from a hospital social worker, comprising both plentiful written information and personal support. More commonly, information and advice was given about specific aspects of the situation and the carer had to fill in the total picture from other sources.

GPs typically provided information about the medical condition of the person cared for and the procedures involved in the treatment, such as specialist referral, but rarely considered the implications for care at home. One carer, for example, had seen both her GP and her husband's consultant when his condition had worsened two years previously but neither was forthcoming with additional support and advice. An MS nurse offered counselling but was unable to give the practical information about services and benefits which the couple needed. In the end, the carer contacted the local CAB who provided excellent support through their home visiting service. In another case, the GP provided an element of practical support through nursing auxiliaries but it was only when the carer encountered the Alzheimer's Disease Society at a stall in a local street fair that he found out about Crossroads and was told about practical matters such as tax relief and gaining power of attorney.

One carer of a man with mental health problems had found her approach to the GP most unhelpful:

> *"....useless, they said we're helpless, there's nothing we can do unless he's sectionable, bye, bye."*

A small number of carers had made little progress in gaining information since they first began to care. One remembered having to fight hard for disability living allowance for her sister who had previously been on unemployment benefit. A social worker at the hospital had actively supported her claim. Having eventually won this battle, however, the carer assumed that DLA was all she was entitled to. Since then she had approached no-one else for help, and nothing had been offered.

➡ *Help for themselves*

The carers' search for information was focused almost exclusively upon services for the person cared for. Three carers among the interviewees had sought help specifically for themselves and this had taken the form of counselling, while a number of others had health problems of their own which had led to hospital admission or other medical treatment. One carer had been told by her son's psychiatrist that she needed counselling but she said she did not have time for it.

Most carers relied on informal networks of family and friends for emotional support, but several said that they had benefited from the sympathetic presence of professionals. An example, was a carer who had regular support from a Macmillan nurse whom she felt she could ring up at any time. Some carers said that they did not need support for themselves providing that services were reliable, or that they just accepted the situation and got on with it - *"I just plod along",* as one man put it.

2 b) (ii) Social Services Assessments

➡ *The prevalence of assessments*

Just over half of the carers interviewed had discussed the help and support which they needed with Social Services during the past two years. In almost all cases, the carers spontaneously referred to these discussions as assessments

The proportion of carers who had not participated in an assessment was larger than in several of the other Carers Impact sites but possibly reflects the very open recruitment strategy which Bolton adopted for this study rather than any significant differences in practice.

The reasons for an assessment not having been undertaken were various. In one case, the carer was receiving regular support through Crossroads and nursing auxiliaries but there was no monitoring of the situation other than the district nurse coming up from the health centre from time to time with her notes to check that everything was all right. Another woman had refused an assessment but had informal contact with her social worker which she found helpful. A third carer was isolated from all services and unaware of the possibility of assessment, even though her expressed need for support was acute. One person was having his circumstances regularly reviewed by the community psychiatric nurse, but not the Social Services Department, and two people with long-term chronic illness had had no recent contact, but had had contact in the past.

➧ *Circumstances of assessments*

In several cases, the assessment had been triggered by a crisis, notably an admission to hospital for the person cared for and, in one instance, for the carer. The initiative for arranging these meetings had been taken by the hospital social worker. This worked well in providing a link with community services so long as the hospital was in the Bolton area but there were examples of communication difficulties where the admissions had been to hospitals outside the district. In one case, the carer had lost contact with Social Services when she moved to Bolton a year ago and had had to get back in touch with the hospital social worker who had first dealt with her mother's case in order to reactivate services. Another carer had been admitted to a Manchester hospital following a serious crisis in her own health; upon discharge, her case was referred to a local social worker but she felt that the lack of input from the hospital into the subsequent assessment had been disadvantageous to her.

Assessments also took place in more routine circumstances, either as part of an ongoing review process for the person cared for or in response to an identified need for an adjustment to the existing pattern of support.

➧ *Assessment settings*

Assessments were most commonly carried out by a single social worker, either at home or in hospital prior to discharge. One carer, however, had attended large meetings of professionals at hospital and at her husband's temporary nursing home. She had found the sheer number of people involved (up to 9) intimidating, giving the impression that she and her husband were on trial. On the other hand, the parents of a man with learning disabilities were critical of the poor professional turn-out at their son's regular review; only his key worker had been present at a meeting the week before, the social worker and a representative from his further education college having failed to turn up. However, another parent caring for a person with learning disabilities was happy about the regular assessments and reviews. She commented on the professional way they were run, and they were useful to all concerned. From the carers' perspective , it was important that those attending assessments had an identifiable contribution to make, were well-informed about the situation and had the authority to act.

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. On the whole, this was not seen as an issue, although one carer was critical that his wife had virtually been ignored during the meeting despite being perfectly capable of speaking for herself. Most carers believed that their own wishes and those of the person cared for were closely aligned; where there were differences - usually the other person wanting less help from outsiders than the carer considered necessary- the carers felt that they had been adequately aired during the assessment.

The carers had to rely on their own recollections for details of what had been agreed in the course of the assessments. While most carers believed that a written record had been made of the needs of the person cared for, only four had received a copy. None considered that a separate record had been made of their own needs.

➡ *Carers' experiences of assessment*

On balance the carers perceived those who undertook the assessments as sympathetic, professional and capable. One went so far as to say: "*She's gorgeous, I wouldn't change her for the world.*" There were, however, some dissenting voices. One man complained that the social worker who came, while perfectly friendly, seemed poorly trained for the procedure and gave the impression of knowing rather less about services than he did. Another woman felt that her own serious health needs had been considered only in relation to her capacity to care for her seriously disabled husband and that the two of them had been "lumped together" inappropriately during the assessment. She was particularly annoyed that her own Macmillan nurse had either not been invited to assessment meetings or had been notified too late.

There were some criticisms of the thoroughness of the process. Professionals were guilty at times of assuming that carers knew more than they really did and of failing to bring up relevant information. They were also accused of skimming over the surface of difficult problems, taking for granted the carer's willingness to cope with stressful demands without helping them to consider the full implications. As one woman put it, "*They ask 'Are you happy?' and you say 'Yes', but you don't really know what to expect".* The carer whose husband had regular reviews with the CPN commented that the process was completely irrelevant to their lives.

Most carers considered, however, that the assessment 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 as important an outcome as extra help. One carer insisted that regular reviews were undertaken as a means of keeping the attention of professionals focused on her son's case even though she identified little benefit for herself.

Ideas for improving the usefulness of the assessment process included placing more emphasis on the carer's needs, especially where the carer's own health was at risk; adding a stronger health dimension to the assessment process; ensuring that health and social services worked co-operatively to find solutions; and eliminating unnecessary paperwork when there was no prospect of services being subsidised or provided free.

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 there were instances of emergency packages of care being organised where carers had had health crises of their own.

Some of the older people cared for had complex packages of care that included homecare support, a regular sitting service from Crossroads, day care and residential respite care. Others received one or more of these elements. Among the younger people with physical and learning disabilities, there were similar variations in the complexity of their support systems. A few required regular nursing care and homecare, while others functioned quite independently in the home and attended outside facilities mainly for social contact and stimulation.

A few carers received little or no support in the community, other than occasional contact with their GP and perhaps attendance at hospital clinics.

Many of the people cared for attended day centres for at least part of the week. Some younger adults with physical or mental health problems had tried a day care service in the past but found that it was not what they wanted. This put additional strain on the carers who would have liked to have had the time off during the day, but accepted the wishes of the person they cared for.

Respite care was a feature of the lives of most, but not all, of the people cared for. As with day care, there was sometimes resistance on the part of the person cared for.

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.

The people interviewed and attending focus groups included a number of carers caring for an adult with mental health problems. In these cases the health services were a much more prominent feature of their lives than social care services. Where regular contact with community psychiatric nurses and community support workers could be relied on, they were prominent within the carers' support systems.

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 third gave an unequivocal "yes". The others expressed varying degrees of doubt about the adequacy of service.

Those who answered along the lines of "yes, but..." were generally satisfied with the level of support which they had at present but had worries about emergency back-up or about further help being available in the future. Some identified a need for additional inputs from existing services but, even so, tended to want only small increments in practical support or more time to talk to specialists such as psychiatrists.

Those who considered that the level of support was *not* adequate included one woman who was not receiving any services other than benefits, another whose husband had been temporarily withdrawn from day care and respite care because of his adverse reaction, and carers who were critical that services were insufficiently sensitive towards their own needs. "*I could do with being asked whether I would like a week-end off",* said one carer.

The "don't knows" were people who felt that they were insufficiently informed about the range of services available to offer an opinion about whether their own support was adequate.

The carers interviewed generally 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.

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 feel that they had been able to choose from a full menu of support services. They said this was either because no-one had told them about what was available or because support options were simply not available. They did not necessarily mind the lack of choice so long as what they did get was of good quality and appropriate to the needs of the person cared for. Some, however, were frustrated by the lack of options and by what they saw as a "take it or leave it" approach on the part of professionals. "*There's no choice at all. If you don't like it, tough*", said one carer.

Two of the carers in the focus groups had made assertive choices in the face of opposition. One had insisted that her husband with Alzheimer's disease be discharged from hospital against medical advice. She was told that that it was "on her head". It took some time for her to get support services at home and she took this to be an indication of disapproval of her actions. Another carer wanted to organise independent living for her son with multiple disabilities. She had asked for home care to support him in an adapted bungalow but he had been offered sheltered accommodation because it is was cheaper option for Social Services.

A few carers were offered choices between alternative providers for respite care and day care, and one had been given a choice between a male or female sitter. In general, however, they simply accepted the particular service offered. Once again, this was quite acceptable where the quality was good but there was an element of dissatisfaction, particularly about the lack of choice over private providers of homecare.

The carers said that the welfare of the person cared for was always central to the decisions about the services they received and that 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 concerned had no speech.

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, but often, additionally, because their mental health or physical incapacities did not enable them to express choices. One carer of an adult with learning disabilities said that although his weekly programme of activities was quite varied and full, the framework was rigid, allowing little scope for shifting activities to different days.

2 c) (iv) Current problems with services

In the majority of cases, support services were central to the carers' coping routine and were valued as such. Inevitably, there were criticisms when services fell short of expectations and needs. These have been grouped under key headings.

➡ *Difficulties of access*

Some carers had had difficulty in contacting social workers. One said that you had more chance of getting an audience with the Pope than of contacting her social worker; others had experienced long delays in being contacted after their initial approach, and had not had their telephone calls returned. There were also complaints about social workers (and community psychiatric nurses) failing to keep appointments. When no explanation or apology followed, the carers felt that the professionals concerned had little regard for their time.

Access to services in times of emergency was a frequent concern for carers, particularly where they had health problems of their own. They worried about how the support system would hold together if they were not there to co-ordinate it, and they disliked the idea of having their role taken over by strangers. One said, *"I need to have something in place so that it doesn't all collapse if something goes wrong."*

At a very practical level, gaining access to incontinence supplies was identified as a key issue. Where the need for free supplies had been accepted, the service appeared to work well. However, some carers seemed to have little prospect of their needs being met. One man recalled how his doctor had put his wife on the computerised waiting list one year after her discharge from hospital; four years later, they were still having to buy pads privately. Another carer whose husband had been on the waiting list for thirteen months had recently rung to enquire about progress, only to be told that he was now number 372 on the list and would move up only if someone died. As these carers pointed out, being on a list which did not move was equivalent to being denied the service, but less honest. In the meantime, the carers found that the costs of buying their own supplies was mounting. In one case, a recent hike in the price of a certain pad meant that the carer was having to pay £64 per month.

These problems were compounded by the practical difficulties of obtaining supplies. One man said that pads could be obtained only from Lever Chambers, which meant taking the car into town and finding a parking space. The journey had to be carefully planned since the office was only open for an hour but, even so, he frequently discovered that they had run out of the type of pads which his wife needed. He concluded that this was the one service which nobody seemed to care about.

Transport was another barrier encountered by carers. On the whole, day centres provided their own transport but there were instances where carers were taking and collecting the person cared for, with a consequent reduction in their own “free” day. Carers of adults with learning disabilities had discovered that while a range of community education facilities was available, the lack of flexible transport options in practice restricted access.

➡ *Inadequate information*

Carers identified several ways in which their information needs were not being met.

Many felt that the condition of the person cared for had not been properly explained to them by medical staff, either at the point of diagnosis or during subsequent treatment. Consequently, they did not know what to expect or what the demands on them would be. Inadequate information about changes to medication regimes was a particular grievance for carers of people with mental health problems.

A lack of good, comprehensive financial advice meant that carers remained ignorant of their benefit entitlements for long periods and were unable to plan for the financial consequences of lifestyle changes, such as giving up a job.

Some younger carers said that they lacked information about realistic educational opportunities which might help them in the future.

➡ *Limited availability of services*

Many carers would have appreciated extra amounts of the services which they already received, particularly day care and respite care. Some services, however, appeared to be in such short supply that they were unable to offer a meaningful level support. Specific deficiencies were identified in relation to speech therapy and physiotherapy following hospital discharge. Night-time homecare was said to be unavailable because of overbooking, despite recent publicity about a 24-hour service. Sometimes basic supplies were lacking. One carer was told that no extra bedding was available when the person she cared for complained about being cold in her hospital bed, and she was also forbidden to bring any of her own in.

➜ *Services not appropriate*

Day care and residential services were not always acceptable to the person cared for, and their reluctance either eliminated or reduced the support which the carer might otherwise have received. One of the carers in the focus group said that her son was sensitive about accepting respite care and would only go if it was presented as a holiday. However the only respite facility on offer was in Bolton, which made it less credible. Another carer whose husband had physical disabilities described how he had tried residential respite but was reluctant to use it again. She had then tried domiciliary respite but the organisation it required of her meant that it was not worth the effort in future.

Even when the person concerned attended these facilities without complaint, the carer would sometimes worry about whether the care was suitable. There were particular concerns about the level of stimulation offered by day care and respite care where the person cared for had communication difficulties which prevented them from spontaneously joining in with set activities. One carer, for example, reported that her blind and deaf mother-in-law "just sat in a chair" at her day centre which she attended three times a week after attempts to involve her in basketwork had failed. Another who was caring for her 84 year old husband with Parkinson's Disease believed her husband's inactivity at the day centre was worsening his depression.

Sometimes the general context was deemed to be unsuitable for the person cared for. For example, a man with severe chest problems attended a day centre where people smoked, with a consequent deterioration in his condition. A more general complaint was about younger people with physical disabilities being integrated with older people for day care and respite care. For example, one young man with multiple disabilities attended a day centre for two days a week which was considered unsuitable because of the lack of companionship. Age appropriate settings were identified as an urgent need.

➜ *Issues of quality*

Continuity of care was of primary concern to the carers and was most likely to be lacking in homecare services and hospital settings. Carers disliked having a stream of paid carers coming into the home, both because this was unsettling for the person cared for and because it was difficult to establish consistent expectations about what was to be done. There were sometimes unacceptable variations in the competence and experience of individual workers, undermining the overall quality of the service. Homecare which was directly provided by Social Services was said to offer better continuity than that contracted through private agencies.

Discontinuities in hospital care were seen as particularly damaging by carers of older people with Alzheimer's. Several were reliant upon hospital care for respite, and in one case the person cared for appeared to be hospitalised on a semi-permanent basis. It was of great importance to the carers that the older person's emotional and physical needs were fully understood while in hospital and that their medication was properly administered. Too often, however, changes in the staffing of the ward meant that information was not passed on and that standards of care fluctuated. One woman had lobbied hard for a co-ordinated team approach to her husband's care but nonetheless felt compelled to spend up to three hours a day with him on the ward, undertaking most of his personal care.

A lack of attention to detail was not confined to hospital care. Comments about care in a nursing home included that the person concerned had come home with an infection, and, in another instance, had suffered the indignity of being left with her skirts up around her waist. Sloppiness on occasion affected services provided at home, particularly where the carer was not on hand to supervise. Thus, for example, an older man with dementia who lived apart from his carer was visited several times a day by district nurses who filled his nebuliser but did not stay to ensure that he took it correctly, with the consequence that he often received no medication.

Carers sometimes queried whether professionals used their time to best effect. One suggested that the quality of the service given by psychiatrists would be improved by longer appointments and more home visits. Another was critical of the value of assessments undertaken in hospital by occupational therapists, commenting that these threw little light on how the person would be able to manage at home. And the mother of a young woman with mental health problems considered that the combined efforts of a social worker, a psychiatric nurse and a dietician had been wrongly directed towards helping her daughter with tasks, such as cooking and shopping, which she was already able to manage, while her real need for daily supervision of her medication remained unmet.

2 c) (v) Help from the GP

Carers' views on the help they had received from their GP varied tremendously from the carer who said that the GP was "wonderful - out of this world" to another who had found hers insensitive and unsupportive. The balance was towards those who had been helpful; however, this help had usually followed a request from the carer rather than a spontaneous recognition by the GP of the carer's needs. A low level of carer awareness was the norm.

The help given by the GP centred on the immediate treatment of the medical condition of the person cared for. On occasion, however, the GP did act as a point of access to other services - such as 24-hour care for one carer and counselling for another.

In general, GPs were not considered to be good sources of information. They would answer questions if asked but did not volunteer information and were not thought to be well-informed about services.

2 c) (vi) Liaison between services

Carers were sceptical about the how far there was liaison and communication between the services which provided their support. Only two of the interviewees said that this happened on a regular basis with review meetings attended by all the services concerned. Another reported a series of crisis meetings involving a large number of professionals following her own admission to hospital. A few carers considered that there was probably a degree of "behind-the-scenes" liaison of which they were not directly aware, or a partial liaison involving some services but not others. On the whole, however, they did not believe that liaison took place to any significant degree.

The carers expressed mixed views about this. One the one hand, liaison was not necessarily seen to be an unqualified good. For example, one carer suggested that the community psychiatric nurse came to their home to spy on them for the psychiatrist, while another felt that she and her husband had been at the centre of a battleground between professionals who were trying to push the costs of services onto each other.

On the other hand, poor liaison could result in acute and even life-threatening predicaments for carers. One woman recounted a failure on the part of her husband's psychiatrist to inform her GP about a major adjustment to her husband's medication, or to explain the new regime to her. The outcome was that her husband had an emergency admission to hospital and nearly died. A less dramatic but nonetheless frustrating experience was related by another carer who reported a lengthy dispute, accompanied by "trails of professionals through the house", about whether the hoist she had requested for her husband was a health need or a social need. At one point, the order for the hoist was abruptly cancelled when he was admitted to hospital and she had to begin the whole procedure again following his discharge.

2 c) (vii) The impact of services

The carers interviewed were questioned 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 an enormous impact on the lives of carers. The time off provided through day care and respite was particularly important, and some carers went so far as to say that it was essential to their personal survival. This time was often used simply to catch up on routine chores and family business which could not be accomplished in the presence of the person cared for. One woman, for example, said that her days off allowed her to do the cleaning, the washing, the ironing and visiting her mother in an old people's home. Although there was little scope for relaxation or personal fulfilment, the crucial factor was being able to choose how to use the time without constant interruptions.

A few of those interviewed considered that they had no extra time for themselves. This was usually because the person cared for was not attending facilities outside the home, or because the amount of external care was limited. Being entirely reliant on domiciliary services created its own pressures. Feeling that their home was never their own because of the constant influx of care staff was a particular source of strain. One woman said, *"I have less time to myself. I'm constantly up and down letting them in. And they need advice all the time, but if you do tell them they don't like it."*

When asked about the difference that services made to the people they cared for most carers emphasised the benefits 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. One woman described how her adult son's weekly routine had given him confidence, independence and motivation. Without the stimulus of his various activities, she felt that he would probably be at home watching television all day. Homecare services were considered essential to the continued physical well-being of the person cared for and, once again, they offered valuable social contact.

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.

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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.

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	Long delays before they get back to you Professionals do not listen to the carer Not being told enough	Proper communication and co-ordination Being told the truth Respect for the carers wishes
Easy access to services	Carers inhibitions about asking for what they are entitled to Long delays before they get back to you	Instant response in a crisis
Good access to information		Carers centre with lots of leaflets, etc. Information from the consultants in hospital
Emotional support	Caring for someone puts a strain on the marriage Lack of appreciation	Support from other family members Going to carers meetings

Desired Outcome	Factors which hinder	Factors which help
Having a life of your own	Loss of confidence Job prospects for carers are very poor Poor health of the carer Too much hassle to go and join things	Social contact to retain your sanity Paid employment, for meeting people and maintaining independence Educational opportunities for carers Not feeling guilty when you go away
Time off	You are on duty all the time Expense of respite care Constant demands day and night Person cared for refusing respite	Carers need time off Carer to accept their own needs A friend for the person cared for would make it OK for the carer to have time off
Trust	Loss of confidence Being tunnelled into thinking that no one else can help Succession of different carers	Coming to terms with the fact that someone else can care Counselling and assertiveness training Building up a relationship of trust with the paid carers Having an understudy, someone you can trust Building up the time at respite A safety net for when things go wrong
A decent income	Job prospects for carers are very poor Charging for services Loss of income and pension rights when you give up a job	Part-time work Carers to be valued including in cash terms

Desired Outcome	Factors which hinder	Factors which help
Reliable and appropriate services of acceptable quality	You have to take what they are willing to offer not what you would like Not turning up when expected Inappropriate day care Problems with transport Not enough support Not enough services and not when you need them	Services that fulfil the needs of the person cared for and therefore of the carer Qualified and experienced help Using common sense Continuity of carers Attention to detail Good forward planning

2 b) Carers views on improvements needed in Bolton

➡ *Information*

Carers saw their information needs as central and had a variety of suggestions for improvements.

In general, they wanted professionals to be more forthcoming with help and advice, particularly in the early stages of caring. Hospital consultants were seen to have a special responsibility for putting carers in the picture about the condition of the person cared for and the implications for their day-to-day care. The de-coding of professional jargon into comprehensible language was essential. Alongside the provision of information, they wanted to be offered training in skills such as lifting, to prepare them for the demands to be made on them.

Comprehensive and reliable information about benefit entitlements and the range of support services was seen as vital. They felt that carers should be informed about carers support groups at an early stage since these usually offered good information as well as emotional support. Carers also wanted someone to talk to about their pension rights and legal status so that they could make informed choices, for example about giving up work to care.

One specific suggestion was for a carers information pack, to include contact points, and directories of voluntary organisations. Another was to provide carers with access to the Internet. Someone else said that there should be more triggers within the system, such as the award of Disability Living Allowance, which ensured that carers were identified and presented with information. This carer felt that the existing procedures for registering people as disabled were ineffective, commenting, *"It's as if they put your name in a book and then shut it."*

➡ *Advice and advocacy*

Carers said that they would like access to advice and advocacy services which went beyond the straightforward provision of information. They identified a need for a "one-stop shop" which could offer help with identifying benefit and service entitlements and filling in the necessary forms. Someone to support them in their dealings with statutory agencies was also important.

➡ *Emotional support and counselling*

Carers believed that emotional support and counselling should be recognised as specific requirements of people in their situation and, as such, should be offered routinely. In particular, they wanted counselling to help them work through complex issues, such as whether to place the person they cared for in a residential home.

➡ *Holistic support for carers*

Carers wanted support services which adopted a holistic approach to meeting their needs and those of the person they cared for. It was important that someone other than the carer took responsibility for co-ordinating provision, and they wanted to have services which fitted around their needs. At present, they felt, it was more a question of the users and carers fitting into the system.

Greater responsiveness was to be part of this new approach. Carers wanted to be comfortable about asking for help, without being made to feel demanding. They felt that they should not have to fight for services, or wait for them when they were urgently needed. Recognition of their personal and social needs should be included. One suggestion was that every carer should have two full days and nights off a week, because this would be expected in any other job.

➡ *Back-up support*

Carers wanted the reassurance of reliable back-up in an emergency or on more routine occasions when regular care arrangements had broken down. It was important, however, that the person cared for was not subjected to an influx of strangers. One suggestion was for a trained “understudy”, perhaps provided through a voluntary scheme, who would build up a relationship with both the carer and the person cared for and become familiar with the details of the caring role.

➧ *Hospital in-patient services*

Carers argued for a number of improvements to in-patient services. Those caring for people with mental health problems wanted more acute beds (with easier routes to compulsory admissions) and more concentrated attention from psychiatric staff. There was a specific request that people suffering from mental illness should be separated from those with alcohol and drug problems.

The quality of the physical care provided in hospital was a key issue for carers. Those looking after older people with dementia were particularly concerned about their vulnerability in the relatively impersonal setting of a hospital ward and felt that the staffing systems undermined consistent physical care. Some felt that adequate care could only be guaranteed if the carers themselves continued to perform key caring tasks while the person was in hospital, and this was resented. More attention was thought to be needed to developing team approaches to meeting personal needs in a consistent way.

➧ *The transition from hospital to home*

The carers’ experience was that hospital discharge was often poorly managed. They asked for better planning to ease the transition from home to hospital. It was suggested, for example, that stroke patients were left on the acute wards for too long and that they should spend more time in the rehabilitation unit prior to discharge. Linked with this, carers needed more detailed advice and demonstrations about aspects of the care which would be required at home, such as washing and lifting. Another suggestions was that assessments by OTs in hospital should take into account the realities of the home environment.

Carers wanted greater continuity between the care provided in hospital and that which was available when the person came home. In particular, they wanted someone from the hospital staff to act as a personal link. They also looked for improvements in the post-discharge provision of physiotherapy, speech therapy and occupational therapy.

➧ *Community health services*

Carers would like more health services to be provided in the patient’s home. These might include physiotherapy, consultations with the psychiatrist, and a 24 hour emergency service for people with mental health problems. They felt that provision of home-based chiropody should be restored following recent cuts. Better instructions and demonstrations for the use of special equipment was another specific need. The main improvement which carers looked for in their GPs was a more carer-friendly attitude and a greater readiness to offer information.

➡ *Incontinence services*

Key requirements here were a service which was free at the point of need and which provided supplies through local health centres rather than through an inconvenient central distribution point. The existing computerised waiting list was felt to be a nonsense.

➡ *Social work staff*

Carers wanted their social workers to be more accessible. Greater consistency and speed in answering telephone calls were needed, particularly in a crisis. Carers would also appreciate advance notification by social workers of their inability to keep appointments. More continuity of personnel was another plea; the experience of carers was too often that "good people move on".

It was felt that the value of the support offered by social workers could be improved by better communication between different parts of the service, in particular between hospital social workers and those in local offices.

➡ *Home care services*

Carers wanted greater continuity of care workers, and assurances of adequate vetting and training. Many would appreciate a late evening service and an opportunity to use night-time care. However, they felt that they should be given full information in advance about the costs of accepting extra care.

➡ *Day care*

Day care was central to the coping strategies of many carers, and there was a widespread demand for more care to be available during the week and at week-ends. Carers did want to be reassured, however, that day care staff had appropriate training, for example in meeting the needs of people with dementia. There was also a request for more age-appropriate day care for younger people with disabilities.

➡ *Meeting the long-term needs of people with learning disabilities*

Better planning for the long-term future of people with learning disabilities was sought by their carers who said that there was too much crisis management and too little exploration of the preferences and wishes of the people concerned. One carer said that the option to live independently should be recognised as a right once the person had reached the age of 18; however, this recognition had to be supported by individualised planning and specific funding.

Some carers also wanted opportunities for paid work to be opened up to people with learning disabilities, without the risk of benefits being cut when jobs did not work out. They argued that the therapeutic and integrative benefits of work in normal settings justified special treatment under the benefits regime.

➡ *Transport provision*

Carers believed that transport needs should be taken into account and planned for when those they cared for were offered access to external facilities such as community education. Unless transport arrangements were seen as part of the provision, many people would be denied access to valuable opportunities.

➡ *Services for Asian Elders*

Two of the Asian carers interviewed raised some points about the specific requirements of the Asian community with regard to care for older people. Given the stigma attached to entering residential care and expectations that family members will care for elders, it was suggested that the procedures for assessing grants for adaptations to the home should be more sensitive to the circumstances of Asian families. Another suggestion was that day care for Asian elders should be widened in scope, in particular to enable younger people to attend while they are still willing to go out and meet people. Some of the older people are frightened of going out, and do not adapt easily to day care.

Appendix 1: Summary of Characteristics

Carer

	Gender		Age					Ethnic Origin				Marital Status			
	Male	Female	under 30	30-44	45-59	60-74	75+	White British	Asian/ Indian	Asian/ British	Pakistani	Separated	Widowed	Single	Other
Focus Group Totals	5	26	0	2	16	12	1	31	0	0	0	1	3	4	2
Interview Totals	3	17	0	4	7	9	0	17	1	1	1	0	0	2	0
GRAND TOTAL	**8**	**43**	**0**	**6**	**23**	**21**	**1**	**48**	**1**	**1**	**1**	**1**	**3**	**6**	**2**

Person cared for

	Relationship to carer							Gender		Age					
	Parent	Grand-parent	Brother/sister	Spouse	Son/ Daughter	Partner	Other	Male	Female	under 18	18-30	30-44	45-59	60-74	75+
Focus Group Totals	15	0	0	8	7	0	3	16	17	0	5	2	2	6	18
Interview Totals	2	0	1	13	3	0	1	13	7	0	0	5	2	8	5
GRAND TOTAL	**17**	**0**	**1**	**21**	**10**	**0**	**4**	**29**	**24**	**0**	**5**	**7**	**4**	**14**	**23**

	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 / drugs problems	People with mental health problems	Older people with menatl health problems	Older people with physical disabilities	Older people with mental health problems and physical disabilities
Focus Group Totals	15	16	1	21	17	0	2	0	16	7	12	5
Interview Totals	18	2	0	10	15	0	2	0	8	3	9	2
GRAND TOTAL	**33**	**18**	**1**	**31**	**32**	**0**	**4**	**0**	**24**	**10**	**21**	**7**

How carers found out about the Carers Impact Project *(interviewees only)* *Note: Some people heard through more than one source*	
Bolton Carers	8
Social Worker	2
Asian elders day care project	2
Crossroads	1
Day centre	1
Form in Council offices	1
Bolton Evening News	1
Alzheimer's Support Group	2
Respite home (carers group)	1
Housing Association	1
Meeting in Tameside regarding Carers Impact (1996)	1
Don't Know	2