King's Fund

Carers Impact Project in Tameside

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

Hilary Bagshaw, M.A., C.Q.S.W
Judith Unell, Ph.D

QBAN (Kin)

KING'S FUND LIBRARY
11-13 Cavendish Square
London W1G 0AN

Class mark QB AN	Extensions Kin
Date of Receipt 10/8/05	Price Donation

Contents

1 Introduction

2 What the carers told us

3 Key Messages

Appendix 1 Report on consultation with Asian Carers

1 Introduction

1 a) Who we spoke to

Thirty-nine carers were involved in the research exercise. Twenty (including two couples) were interviewed in their own homes; the remainder took part in four focus groups. Two of the groups had six participants, one had five, and one had two. We had originally intended to have 10 participants per group, in three groups, but it proved too difficult to persuade carers to attend a group session.

More women than men were involved in both groups and interviews. However, the men were well-represented considering that they are likely to form a minority of the carers in Tameside. Four men (21%) and fifteen women (79%) attended the groups. Among the interviewees, there were 8 men (40%) to 12 women (60%).

Almost half of the people attending groups were parent carers (9 out of 19), and they comprised a third of the interviewees (7 out of 20). Spouse carers were the next most common (5 in the groups and 7 interviewees). Otherwise the carers were related to the person cared for as grandparent, sister, brother, granddaughter, son, daughter, or son/daughter-in-law. There were no unrelated carers in the sample.

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 half 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. In smaller groups, the participants were asked to consider the factors which helped the cameo carer in their caring task and the factors which got in the way. 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. Once again the carers were asked to consider those things which helped them in their caring task and those which got in the way. They were prompted to think about the people who helped them and the practical support received. Their replies were recorded on the flip chart.

- Questions about the help received. Each person was asked the following questions:

    - *Do you feel that you are receiving all the help you need?*
    - *What other kinds of help would be useful to you?*
    - *How would you find that help?*

  Individual responses were recorded once again and other members of the group were invited to contribute ideas for kinds of help and support that might be useful.

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

1 c) Presenting the findings

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

1 d) Carers from Black and Minority Ethnic Communities

A focus group for carers from black and minority ethnic communities was commissioned at the same time as this research. The experience of carers from black and minority ethnic communities will be integrated into the overall feedback to be considered by the Carers Impact Steering Group.

A report on this focus group, prepared by Ashok Ohri, OSDC Ltd, is included as appendix 1.

2 What the carers told us

2 a) Caring background

2 a) (i) The person cared for

The people cared for covered a broad range: older people with the physical and mental health problems associated with advancing age; adults with physical and/or learning disabilities; and children with physical and/or learning disabilities. The youngest person cared for was seven years old and the oldest was ninety-four.

All but one of the interviewees belonged to the same household as the person they cared for while in the focus groups there were a few who cared for someone who lived elsewhere.

There was great variation in the detail of the caring tasks required. At the lightest level the person cared for required help with mobility, getting in and out of the bath, getting dressed and having food prepared. At the heaviest level the person required carrying, toileting including changing incontinence pads for double incontinence, feeding and constant supervision. Within the interview group, most of the people cared for required some attention during the night. Some of the people cared for by carers in the groups and two of those cared for by an interviewee had challenging behaviour and could be violent, or behave in socially unacceptable ways. In such cases, the caring task extended well beyond the provision of physical care.

2 a) (ii) Length of time caring

Most of the carers had been caring for a long time and all described themselves as the main carer. Only one of the carers interviewed had been caring for less than five years, and most had been caring for considerably longer. In the case of the carers who were parents, the caring task had spanned the lifetime of the child. Where the child was now an adult, the parent therefore had a long term perspective on the caring relationship and the changing fashions in service provision over the years. One parent carer remembered with humour the days before 1974 when the Welfare Officer used to pay her an annual visit and ask her if she had accepted the fact that her daughter was handicapped. Now, she commented, you are not supposed to call people handicapped at all.

In the groups there was at least one carer who was relatively new to the task, and who was anxiously seeking information from other group members to help her.

2 a) (iii) Adaptation to role of carer

Among those interviewed, half considered that the demands upon them had increased - in some cases dramatically - during the past few years. The most frequent reason was a physical or mental deterioration in the person cared for but parent carers were more likely to refer to the increased physical burdens of caring for a growing child while those whose children had recently graduated from the education system cited the reduced level of provision now available to them.

Some carers mentioned the difficulties and tensions which they experienced when they first became carers. The husband carers, in particular, confessed to some frustration at having to become the mainstay of the household, responsible for all the household chores and shopping. Three said that they would prefer to be back at work, even though the choice to stay at home had been their own. For these carers one important aspect of the transition had been the change in financial circumstances. One said that this had been a problem at first but they had learned to live under a new regime.

For the parents of children with disabilities, the moment of diagnosis had often been experienced as a crisis. One parent said that she had refused to believe that her child was not developing at a normal pace when first told the news and it had taken time to accept the diagnosis. Her experience of lack of support at this difficult time was shared by other parents. Carers had not always found medical staff helpful in the way the information was given. One parent had been told her child's diagnosis by the physiotherapist, because the clinical staff had not informed her.

In most cases, however, the carers could not identify a specific point at which they had recognised a changed responsibility towards the person cared for. Most had accommodated themselves gradually to the demands of the caring task and now accepted it as an everyday job which they simply had to get on with. Having less time to oneself and being unable to plan ahead were acknowledged as frustrations but these curbs on personal freedom seemed to be borne with little resentment.

2 a) (iv) Social needs of carer

All the carers acknowledged the need for social contact independent of the person cared for. At the same time, the caring relationship was generally regarded as positive. A considerable majority of those interviewed expressed satisfaction about their role, mainly because of their affection for the person cared for but also for more abstract reasons, such as fulfilling a sense of personal obligation or, in one case, 'doing God's will'. Almost all the carers of adults with physical disabilities made positive comments about the relationship. The people caring for someone with learning disabilities or suffering from dementia were clearly more in need of other social contact, and "more adult conversation" was something desired by at least two of the carers.

Having family members able to take their share of caring, and informal networks of neighbours and friends to maintain contact and provide emergency support were key elements in most carers coping strategies. A quarter of the carers interviewed had no such networks and were under great stress.

2 a) (v) Health of carer

Of the carers interviewed, almost half acknowledged health problems of their own. Although these had not arisen directly from the caring task, they inhibited the carers' capacity to cope. In the groups it was rare for the carer's own health to be mentioned. This may reflect a tendency for more active carers to be able to attend groups.

Three of the carers interviewed had had recent hospital in-patient treatment, that had required crisis measures to be taken for the person cared for. Three others had chronic health problems that had considerable effect on their lives and their ability to perform caring tasks especially where physical strength was required as in lifting.

2 a) (vi) Worries about the future

Worrying about what the future would hold was a key element in perspective of the older carers. A quarter of the carers interviewed mentioned this voluntarily, and one said that he thought: "the hard part has got to come". There was a burden of responsibility being the sole or main carer, and a sense of their own deterioration in health and strength.

2 b) Access and assessment

2 b) (i) General patterns

Looking back to the early stages of their careers as carers, all felt that they had lacked information about the services available. Some had been completely ignorant while others had a partial view about specific services. For most the search for information had been erratic and prolonged. Carers of children and young adults who had contact with different service systems at the different stages of development had found that they needed to recommence their search for information at each phase. Finding the help they needed often involved following leads from friends or fellow carers. It had been quite difficult to identify the 'right' professional contact and very few said that they had been approached spontaneously by a professional to discuss the various options for support. Independent advice would have been appreciated particularly by the parent carers who had complex decisions to take about the care and education of their children.

One carer likened service information to a web which was complex and difficult to penetrate. Once inside the system, however, it was possible for carers to feel swamped with information, particularly written materials relating to benefits and practical support. The problem then became one of absorbing and evaluating the information available. The carers expressed a need for personal guidance and support at this stage, and it appeared that the Carers Centre has fulfilled this need very effectively for some carers, although others did not seem to be aware of the Centre's outreach role and felt inhibited by a perceived need to go into the Centre to seek help. Most carers had become aware of the Carers' Centre after approaching Social Services about a particular need. Thus the Centre was rarely the first point of entry into the system, perhaps indicating a need to promote itself more widely in the public domain.

2 b) (ii) Co-ordination of information across service systems

Poor co-ordination between the different service systems in terms of cross-referral and the provision of information was frequently experienced by carers. There was no guarantee, for example, that by approaching one's GP the necessary links would then be made with Social Services. There were certainly examples of good co-ordination at this primary level but most carers needed to find more than one point of entry to the information and support they needed.

For the carers of children in education, the school did function as a point of co-ordination for key services, for example physiotherapy and dental treatment. School reviews provided a specific opportunity for inter-agency liaison. Problems of co-ordination did, however, began to surface once the child left school or college.

Gaining a perspective on the whole range of options available proved difficult for carers, whatever the circumstances of the person cared for. Many had relied heavily upon the experiences of other carers and users as their main source of information, and one carer commented, "You don't find out unless you know someone in a similar predicament".

2 b) (iii) Social services assessments

The information about assessments from the interview group was skewed by the high proportion of carers (almost half) whose only form of support was equipment or adaptations in the home. While it was clear that an assessment of need had taken place in relation to these practical resources, this did not appear to have formed part of a more general assessment of community care needs. Typically, it involved a visit by the occupational therapist to discuss and observe the practical problems faced by the person cared for in performing a specific activity (such as getting in and out of the bath), after which a practical solution would be suggested. The process appeared to be straightforward and efficient, the chosen aid or adaptation being promptly supplied. However, the assessment did not impinge upon other areas of personal and social need and, even within its own particular sphere, did not appear to open up a wide choice of practical options. All the carers concerned said that they and the person they cared for had simply accepted what had been suggested. Most were satisfied with this but one carer commented, "It wasn't a question of 'Is that enough?' or what else might be available."

Many of the carers who were receiving ongoing support found it difficult to say whether they or the person they cared for had received a formal assessment from a social worker. Most had received a visit from Social Services within the past two years to discuss their circumstances but were not always clear about the role of the person who came and of the status of the discussion which ensued. There was a roughly equal distribution of contacts which had been prompted by the carer and those initiated by Social Services. The latter resulted either from a crisis which had brought the caring situation to the attention of the statutory services (such as an emergency hospital admission for either the carer or the person cared for) or from the routine follow-up of families of disabled adults. Contact by carers was related to a request for a specific service or a need for a more general review of the caring situation. One couple who were particularly well-informed about the service system had made a formal request for an assessment of their son's needs.

Within the interview group as a whole, most carers remembered that a written record had been made of the needs of the person cared for but fewer than a quarter said that they had received a copy and none had received a written assessment of their own needs. It seemed that the assessment process was still firmly focused upon the person cared for - none of the carers, for example, said that they had been offered a separate discussion with the person who came to see them. Most accepted this, taking the view that action to assist the person they cared for would in any case help to meet their own needs. They did seem to find it quite difficult to conceptualise their needs as separate and, from this limited evidence, it does not appear that the assessment process has been effective so far in helping them to do so.

Almost all the carers were complimentary about the attitudes and approach of Social Services personnel in discussing their needs. "Relaxed", "friendly", "very thorough", "I felt that I had known her all my life", were some of the comments made. One carer who felt that the visit had been unproductive because none of the day care options available was appropriate for her son nonetheless acknowledged that the social worker had been helpful and positive. Only one carer in the interview group reported a negative encounter which resulted in the social worker being asked to leave. The overwhelmingly positive nature of the contacts gave the carers confidence about making further approaches to the same person for help or information. Although few reported regular contact with a social worker, most said that they knew how to get in touch and would do so if necessary. One carer had already initiated regular discussions to discuss her mother's home care needs. On the other hand, there was a small number of carers who were sceptical about the benefits of further contact.

Most carers reported that their discussions with Social Services staff had resulted in extra services. These ranged from aids and adaptations, which made an instant difference to problems of mobility and personal care within the home, to services which enhanced the social contacts of the person cared for (for example, through a befriending scheme and access to a range of educational classes). In general, however, the benefits to carers were indirect. Only one carer, however, reported increased access to respite and another who had made contact with the Department about the Family Link scheme emphasised that this was in her child's interests, not her own. A different carer commented, "They leave me to my own devices".

2 c) Carers experience of services

2 c) (i) The range of support received

The carers were asked about the support they currently received. Interviewees were prompted with a written checklist while focus group members were invited to describe their circumstances to the rest of the group.

The individual interviews revealed a wide variation in the type and amount of practical support received. One carer received no help at all, mainly because of his father's hostile reaction to any suggestion of seeking services or benefits. For almost half the interview group, the support was confined to aids and adaptations which had been made to their homes. These carers were not receiving ongoing social work support or regular contact, although some were in touch with the Carers Centre. At the other end of the spectrum were a small number of carers who had themselves co-ordinated quite complex arrangements including both statutory and independent services. Several carers relied upon services which were co-ordinated and arranged through Social Services but these formed only a minority of the interviewees.

The focus group members were similarly diverse in the patterns of services they received. At one extreme were carers who shouldered the entire burden of demanding care responsibilities with little or no outside help ('I'm the only service', said one); at the other were carers who had access to multiple sources of support. In between were the majority of carers who received some support but whose daily lives remained heavily dominated by the caring routine.

2 c) (ii) Choice for the carer

Asking carers about the extent to which they had exercised choice over the services they received was not straightforward.

Those carers who saw their support needs in quite straightforward practical and financial terms tended to see choice as a secondary issue. For example, a couple caring for a frail and elderly parent with dementia considered that their needs were adequately met through financial benefits, a supply of incontinence aids and a weekly sitting service. Having received some initial guidance about what was available, exercising choice was of minor importance to them once these services were in place. While carers like these valued the support they received, they did find it quite difficult to say whether this was what they most wanted. This was mainly because they lacked information about what else might be on offer. In some cases, they would have liked services - particularly domestic cleaning - that they knew were no longer provided through Social Services.

Carers whose only source of help was equipment or an adaptation to the home also found it difficult to relate to questions about choice since they had generally accepted what had been suggested. There were, however, some who were critical that there had not been adequate consultation about the range of equipment on offer or about the options for structural adaptations to their homes. In general it appeared that choice was limited in this area and also that assessments for aids and adaptations had not formed part of a broader appraisal of support needs. Thus the carers tended not to see aids and adaptations as part of a wider menu of services from which they might choose. Two of the spouse carers felt that they had made a choice not to seek any further help.

Choice was a more complex and difficult issue where the person cared for was receiving ongoing care from an outside service. This was perhaps expressed most forcefully, both in the interview group and the focus groups, by carers of younger adults with disabilities. The quality and appropriateness of the care offered was of great importance to the carers but they mostly felt that they lacked the information upon which to base a choice and that, in any case, the range of opportunities available was determined in arbitrary ways by 'the system'. For example, the mother of a young man with profound disabilities complained that the hydrotherapy which he had benefited from while at school had been withdrawn as soon as he left. The comment that 'everything stops at 19' was heard more than once during the study.

Choice of educational provision was an issue which lay at the heart of parent carers' concerns. They felt strongly that this was limited for their children, both in terms of the special education options available and in terms of access to mainstream education. Parents of children with physical disabilities saw mainstream education as a vital part of the normalisation of their children's lives but felt that they had to battle hard to obtain it and that even then it was not always implemented successfully. In general, parent carers felt that they were not supported in the exercise of choice in relation to education.

Returning to the group as a whole, even those carers who considered themselves fortunate in the care available were worried that changes could be made to valued services without their views or those of the person they cared for having a real influence. This came up repeatedly in relation to the reorganisation of day care for adults with learning disabilities. The predictability of the existing arrangements was important both to the carer and the person cared for. Impending change brought uncertainty about both the quality and amount of provision. Specifically, there were worries that friendship groups would be split, staff numbers would decline and the choice of activities on offer would be diminished.

2 c) (iii) Choice for the person cared for

The carers found it quite difficult to decide whether the person cared for had a real choice about services. Most acknowledged that they made the major decisions about ongoing care on behalf of their relative or child, particularly where there were severe communication or memory problems. A number of carers said that the person cared for was not able to make a choice. At the same time, it was felt that the person cared for did exercise an element of choice through their behavioural and emotional responses to the care received. Several carers, for example, claimed that they had withdrawn their relative from a care setting following a bout of disturbed or upset behaviour. In this way, they were adjusting the pattern of care to meet the other's preferences. Few, however, would have claimed that the person cared for took decisions about their care in a more formal sense.

Parents of older children did have specific concerns about whether services would adapt to their changing needs, emphasising the need for regular reviews. For example, one parent felt strongly that her teenage daughter should have the choice of a female carer to attend to her personal hygiene. Those whose children were likely progress to independent living pointed out that while the choice of setting was vitally important, it was difficult to obtain impartial information about the alternatives. One carer whose daughter had suffered a disastrous breakdown following placement in a community scheme described her sense of guilt that she had allowed her to move out of the home on a trial basis. Letting go was difficult in any circumstances but caused real anguish when the wrong choice had been made.

In a small number of cases, there was an evident conflict of preferences between the carer and the person cared for. Some carers felt that they could not seek the support which they badly needed because of their relative's resistance to any form of intervention. In other cases, carers recognised that a compromise had to be reached between their needs and that of their relative in order to preserve their own health. Thus, for example, one woman relied upon rotational care for her husband as a central part of her own coping strategy even though he deteriorated mentally when away from home.

In some cases the carer was interviewed with the person cared for present. This limited in two cases the freedom with which the carer could speak about their circumstances, and may have prevented them from airing differences of opinion which they felt to be present.

2 c) (iv) Issues of flexibility and cost

Aids and adaptations were valued for the flexibility which they introduced into the pattern of care at home. Thus a parent carer anticipated that a new ground floor extension for her teenage daughter would free up the family during the morning rush and allow her daughter to get herself out of the house unaided. Ease, convenience and more choice in the daily routine were important outcomes for many carers.

For those carers who were receiving ongoing support, flexibility in the timing of its delivery was important. The carers in the interview group were generally satisfied with the flexibility of provision. They found that the timing of home care could be varied in order to accommodate special commitments, and the small number of carers receiving respite reported that arrangements could be varied to suit their needs, although regular respite was generally preferred. On the whole, these carers felt that their access to services had not been limited by cost. However, one carer who had used her attendance allowance to co-ordinate a sequence of care-givers for her mother during the day considered that she would have been able to arrange further care in the late evening if her resources had been greater.

Day care was accepted as a fixed resource around which carers needed to organise their own routines. Some would have liked a longer break but in general they felt that the reliability of the service allowed them sufficient flexibility to plan for their own needs.

Within the focus groups, issues of flexibility and cost arose specifically in relation to incontinence supplies. Parent carers complained that their supply of pads had been severely restricted - in one case to 4 per day which was exactly half her child's need as originally assessed. These parents questioned the role of the incontinence adviser whom they saw as a gatekeeper rather than an access route, greatly preferring the old system which permitted health visitors to dispense pads on request. These carers had no alternative but to purchase extra pads and believed that the rationing of the service concealed unjustified assumptions about their ability to pay. In the interviews, incontinence supplies caused problems for two carers. Neither had adequate supplies for their needs and therefore had to purchase extra. One of them was having difficulty finding a specialist supplier for pads in the right size, and the other had to provide pads for the day care service to use.

Cost as a barrier to adequate support arose more frequently within the focus groups than among the interviewees. It was particularly an issue where the person cared for had complex physical needs which required high levels of practical support. Resources devoted to extra help meant less money within the household budget for other purposes. For example, one carer felt that the deteriorating condition of her house was undermining her quality of life but that this was an unavoidable consequence of having to pay for the support she needed.

2 c) (v) Quality

The quality of services was a vital issue for carers. Specific concerns were expressed by both the interviewees and the focus group members about the quality of home care provision by private agencies. Those receiving home care directly through Social Services appeared considerably more satisfied. There were complaints that the staff of private agencies tended to be poorly trained, showed limited interest in the person cared for, and seemed always to be under pressure to meet the next assignment. There also appeared to be little continuity, some carers complaining of a stream of different people coming into the home. It was suggested that the growing reliance upon private agencies had sacrificed quality in the interests of efficiency. The knock-on effect for carers was that they enjoyed less peace of mind because their confidence in the service was diminished. One carer in particular felt she had to supervise all the work of the Home Care Assistant.

The quality of care provided in settings over which the carers exercised no control was a source of some anxiety where the person cared for had limited communication skills. Trust was critical and a bad experience could seriously undermine confidence, as in the case of one parent who had discovered bite marks on her son after a spell of respite care. This had strengthened her reluctance to consider day care, and she was now caring for him full-time at home.

A rather different issue was raised by a carer whose elderly mother suffered from dementia and received regular day care in a hospital setting. Although the carer was confident about the quality of physical care her mother received, she worried about whether staffing levels were sufficient to allow her mother individual support and whether the centre was geared to providing enough positive stimulus and occupation.

On the other hand, there were several carers, as noted above, who regarded day care and respite care as a prized and trusted resource. They were nonetheless able to empathise with other carers' difficulties in relinquishing some of their caring responsibilities, and emphasised the importance of gradual introductions in order to build up confidence and of ensuring good communication and feed- back at all times.

Regularity and reliability of support emerged as a quality indicator for some carers. For example the parents of one young man complained that a supported travel plan which had been designed to increase their son's confidence in using public transport had collapsed because of poor organisation.

2 c) (vi) Liaison between service providers

In general carers were unaware of co-ordination between different service providers, except where they provided that link themselves. Few appeared to have ongoing support from a social worker and there was doubt about the extent to which GPs liaised with Social Services. The carers' main contacts tended to be with the providers of the specific services. For example, they would contact the home care provider direct if they needed to change an arrangement. There was little sense of Social Services exercising a watching brief over their needs. However, some did identify a contact within Social Services to which they might turn for guidance if the need arose. The need for an identifiable point of communication was emphasised particularly strongly by the parent carers whose children's needs spanned several service sectors. They talked of their weariness at having to repeat the same information on different occasions to different professionals.

2 d) The impact of services

2 d) (i) General patterns

Within such a diverse population of carers, it was hardly surprising that the perceived impact of services was variable. It was greatest where carers could rely upon a regular time apart from the person cared for, whether through day care, education or respite, and where they had full confidence in the quality of the care on offer. It was least where the support was confined to aids and adaptations which had become assimilated into the basic daily routine and were hardly perceived as an extra resource. A middle group of carers - for example, those receiving a limited home care or sitting service - felt that while the support eased some of the stresses and strains of caring it made only a limited difference to the scale of the caring task.

A good example of maximum impact was provided by a carer who lived with an adult daughter with learning disabilities. Day care met her daughter's need for constant stimulus and for the company of friends of her own age while respite offered a regular 'holiday' to look forward to. Time apart kept their relationship fresh, with new experiences to talk about, and also gave the carer protected time to pursue her own plans and interests. Other parents of adults with learning disabilities referred to the strain of keeping them entertained and motivated. Although the physical burden of care was often quite light, the continuous demands upon their attention were experienced as stressful. In a similar way, carers of older people whose conversation was continuous and repetitive became desperate for some quiet time in their own homes. Several carers pointed out that the whole family benefited from quality shared care which improved the mood and outlook of the person cared for.

For those carers whose primary source of support was home care, the benefit was limited in some cases by the poor quality of the service offered and in others by the limited amount of help or by its unavailability at times which most would have most suited the carer.

2 d) (ii) Aids and adaptations

While regarded by many of the carers as something barely worth mentioning, it was clear that aids and adaptations had a very marked impact on the lives of carers and the people they cared for. In many cases it made it possible for them to continue to live in their own home, to give them mobility around the home and to get out and about.

For parent carers, the inevitable growth in height and weight of the child made the caring task increasingly physically demanding. Aids and adaptations, such as stairlifts, shower chairs and hoists, were able in many cases to compensate for this. The worries that some of the older carers voiced about their own declining strength and ability to care could in some measure be alleviated by the knowledge of the range and ingenuity of some of the aids available.

2 d) (iii) More time for themselves?

Half the carers in the interview group considered that the support they received had released some time for themselves. These were the carers who were receiving a regular break through schooling, day care or a home care service. Only three were receiving regular respite care. For those receiving home care, the time available (generally a few hours a week) allowed them to complete essential chores such as shopping but did not give them significant time to pursue social and leisure interests. Day care and respite care (where available) offered considerably more time for themselves and this had clearly become an essential part of their strategies for coping. Those who lost this support - for example, when a child's formal education ended - found it difficult to adjust to the loss of personal freedom and to the changed relationship which resulted from spending more time together.

2 d) (iv) Respite

The interviewees' experience of a limited supply of appropriate respite care in Tameside was strongly echoed within the focus groups. Carers of older people reported having struggled to find short-stay care, particularly where their relative or spouse was displaying difficult behaviours which made their own need for a break all the more acute. Parent carers found their options diminishing as their children grew older. One mother who had received regular weekend respite through her daughter's placement with a Link family felt that she had no viable alternative once the link broke down. She had tried residential respite but it had proved unsuitable. Another parent whose child had moved into residential care at 19 years old felt that she could have coped longer at home if respite had been available. Time to spend alone with their partners or to devote to other children in the family was a need which parent carers expressed particularly strongly.

Where respite care worked well, on the other hand, it was highly valued both as a source of support for the carer and a good experience for the person cared for. A foster care scheme for adults with learning disabilities drew particular praise from one carer whose daughter had formed a firm friendship with her foster carer and looked forward to her week-ends away with keen anticipation. Another parent described her flexible respite care arrangement of 45 days per year as 'fabulous', both for herself and her adult son. One parent carer described the respite as giving her a break physically and mentally. The fact that someone else was taking the responsibility for the care was as important to her as the physical rest. Such experiences would suggest that the problem of respite care in Tameside is primarily one of supply rather than quality.

2 d) (v) Information and Support

Carers' needs for information both at the start of their role as carer and as the role progresses was much in evidence. In a number of instances the Carers Centre was identified as providing information and support to carers, and this was highly valued. Some carers had received help in claiming benefits, while others attended group meetings and welcomed the opportunities to become more widely informed about issues affecting carers, and to network with other carers. One carer was receiving substantial social and emotional support from the Centre.

The Welfare Rights service had been used by a number of the carers interviewed. Assistance in claiming benefits was very much welcomed and had an impact on the financial circumstances of these households.

2 e) Gaps in services

A number of times the issue of crisis services were raised both in the interviews and in the groups. Carers wanted the peace of mind to know that if anything happened to them arrangements would be made to look after the person cared for. For some carers this would be the ability to admit the person they cared for to an emergency bed in hospital. For others it would be a liaison point where all the necessary services could be contacted and informed of the change of circumstances.

There were some specific instances where the carers felt that appropriate services were not available. One person caring for an adult of pension age with learning disabilities felt that the day care arrangements in a residential care home for older people were not appropriate, as she could not participate in many of the activities. This carer wanted to have special facilities available for day care for older people with learning disabilities, and also informal clubs and social activities for this group of people to attend. Similarly, a carer of an older woman with Alzheimer's disease worried that there was insufficient stimulation for her in the day care setting.

One of the parent carers with a young child with complex disabilities wanted to have more activities available especially during the school holidays. During the school term, the child was stimulated by the educational opportunities provided, but the parents felt at a loss during the breaks.

)4 285786 030004 285786

3 Key Messages

3 a) Desirable outcomes

The focus groups were a particularly rich source of information about the outcomes desired by carers. Through the cameos they were able to apply their own experience in order to identify positive changes needed in the life of the person depicted. These were often at quite a general level but indicated the kinds of impacts which they considered important. The carers in the focus groups and the interview groups were also encouraged to think about changes which would be helpful in their own situation.

The outcomes which they identified as important for themselves and others were:

Desired Outcome	Comments made in the groups and interviews
Being fully informed	Awareness of the full range of services available through comprehensive and well-targeted information.
Emotional support	Involving friends and community members more actively in the caring task. A chance to take care of 'me' / my partner / other children.
Control of your own life	Having positive goals for your life and thinking creatively about solutions. Learning to off-load the guilt and `leave go' from time to time. More control over your own life; a chance to make plans. Having a voice and being able to tell other people what you want.
Time off	Being able to switch off completely from caring from time to time. More freedom to plan and take holidays Enough time to yourself to see friends and simply relax.
Financial security	Financial recognition of the costs of caring.

Desired Outcome	**Comments made in the groups and interviews**
Paid employment	Employment, even if it is just a part-time job where you can meet other people.
Confidence in service quality and reliability	Confidence in the capacity of others to provide care Stability. Peace of mind that the needs of the person cared for will continue to be met.
Opportunities for the person cared for to develop, and to realise their dreams	Confidence that cared for person will have opportunities to learn and develop - particularly important for carers of children and young adults. Help to help the person cared for realise their own dreams.

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

Desired Outcome	**Factors which help**	**Factors which hinder**
Being fully informed	Carers centre which offers both emotional support and plentiful information.	Lack of information about what is on offer.
Emotional support	Carers centre which offers both emotional support and plentiful information.	Sense of isolation/ depression. Attitudes of person cared for e.g. resisting support.
Control of your own life		Sense of isolation/ depression. Over-protectiveness. Lack of trust in others. Own deteriorating health. Attitudes of person cared for e.g. resisting support. Failure to listen to carers' experiences.

Desired Outcome	Factors which help	Factors which hinder
Time off	Regular breaks during the ordinary week. Regular, dependable respite which the person cared for can also look forward to. Rotational care as a useful 'high-intensity' variant of respite. Day care for children during the holidays plus after-school care.	Restricted hours and times of sitting services. Shortage of respite care, particularly for young adults. Holidays are expensive and difficult for carers to arrange. Lack of provision for children during school holidays. Workload imposed by extra washing when incontinence supplies inadequate.
Financial security	Access to welfare rights advice.	Cost of additional services.
Paid employment	Help available at stress points during the day - e.g. getting a disabled child ready for school.	Employers' reluctance to take on people with caring responsibilities.
Confidence in service quality and reliability	Regular, dependable respite which the person cared for can also look forward to. Rotational care as a useful `high-intensity' variant of respite. Not having to explain your situation over and over again to different people. Someone to call on in an emergency who will provide a practical 'quick-fix'.	Uncertainty about future provision -particularly in relation to day care for people with learning disabilities. Poor quality home care Uncertainty about medical intervention e.g. waiting for an operation before making changes in care arrangements. Continuous change of people coming into the home. Failure to listen to carers' experiences. Withdrawal of informal access to hospital beds in an emergency.

Desired Outcome	Factors which help	Factors which hinder
Opportunities for the person cared for to develop, and to realise their dreams.	Separate living accommodation for disabled children as they become adults, giving more privacy and independence all round. Opportunities for children to expand their horizons through new activities & experiences - arts projects, horse riding, wheelchair dancing. Access to mainstream education and other opportunities for disabled children to make friendships with able-bodied. Adaptations which are tailored to the changing needs of a growing child.	Lack of choice over educational provision. Poor co-ordination between children's and adult services.

3 b) Current issues specific to Tameside

Our discussions with carers revealed several topical matters which are causing concern to carers in Tameside. These have been discussed in the main report and are summarised here.

➡ *The availability of incontinence pads*

Apparently arbitrary quotas imposed on the supply of incontinence pads were of particular concern to parent carers. They felt that rationing was quite inappropriate for a service which was so essential to their children's personal cleanliness, and expressed frustration when the service available bore little relationship to the assessed need. The exclusion of waterproof sheets and wipes from the incontinence service was mentioned by both parent carers and carers of older people as another factor adding to the costs of caring.

➡ *Reorganisation of day care for adults with learning disabilities*

Although carers of adults with learning disabilities had received plentiful information about the proposed reorganisation of day care, they felt that neither they nor the person they cared for had been listened to. They were fearful of losing both quantity and quality of service. The choice of companions and activities were cited as important benefits of the existing system for people who needed constant stimulation and interest.

➡ *Quality of home care especially in relation to agency services.*

Particular quality issues for carers were consistent goals and training for staff across the different provider agencies, continuity of contact, spending enough time to do the job properly, and commitment on the part of staff to a quality service. They suggested also that the service should be patch-based in order to promote continuity.

➡ *Access to affordable respite for older people with difficult behaviours.*

Carers of older people with antisocial and repetitive behaviours were under acute stress but seemed to have particular difficulties in accessing appropriate respite care.

➡ *Access to respite care for teenagers and young adults.*

Parent carers suggested that access to regular respite became more difficult as their child grew older and that this imposed considerable strain upon the family, particularly where respite had been available in the past and had been incorporated into the coping routine. The positive benefits to the young person of regular respite were emphasised, for example through promoting personal independence and offering a greater variety of social contacts.

➡ *Access to respite care through the Family Link Scheme*

This scheme was greatly valued by families which had used it but they felt that more link families needed to be recruited so that less time is spent on the waiting list.

3 c) Carers views on improvements needed in Tameside

In this section we have summarised the suggestions for improvements which carers made during the focus groups and interviews.

3 c) (i) Information-giving and communication

➡ ***For parent carers, improved information about care and educational provision at the time of diagnosis, supported by counselling when required.***

Information-giving is too dominated by the medical perspective. Carers need guidance from the outset about the wider implications for themselves and their children.

➡ ***In general, more opportunities to receive information on a one-to-one basis.***

Plenty of written information is available but carers find it difficult to absorb or to evaluate what is relevant. Information-giving needs to be supported by personal contact, whether by telephone or face-to-face.

➡ ***More consultation before changes in the system are made.***

Carers made the point that information is not enough when they and those they care for are confronted with unsettling changes in a valued service. They need to feel that their preferences and those of the person cared for have been fully taken into account.

➡ ***A database to link all carers together.***

A database facility which was open to carers would allow them to communicate directly with each other.

➡ ***More people-centred language.***

Carers wanted greater consistency in the terms used to describe the conditions of those they cared for, and more straightforward language with less jargon and labelling.

3 c) (ii) Assessment and review

➡ ***A more streamlined and co-ordinated assessment process.***

Carers of adults and children with complex needs were particularly frustrated at the repetition and duplication of the information required by different services.

➡ ***A greater willingness on the part of professionals to accept that carers have an expert viewpoint on the needs of the person cared for.***

Carers of adults with learning disabilities felt that they were not always trusted by professionals to speak on their behalf and that a conflict of interest was sometimes falsely assumed. In general, carers believed that professionals should be ready to listen to carers and to act on the information given.

➡ ***More consistent contact with social workers.***

Most carers would welcome regular contact with a known social worker. Existing contact was generally crisis-led and short-term. Someone to talk to about their changing, circumstances was a need expressed particularly strongly by parents of children and teen-agers.

3 c) (iii) Aspects of services

Issues raised by carers about specific services have been discussed above. Other suggestions for improvements were:

➡ ***Appropriate training for carers.***

Lifting and the use of catheters were mentioned as tasks requiring expert instruction. Carers wanted professionals to come into their homes and to take their time.

➡ ***More communication and choice about adaptations involving building work.***

Carers pointed out that major alterations, such as extensions, need to be planned carefully in order to meet the needs of the whole family. Time needs to be devoted to getting it right.

➡ ***Personal back-up in a crisis.***

Carers wanted a call-out service to help them cope during an emergency. They also asked for better emergency liaison between Ambulance Service and Social Services.

➡ ***Better co-ordination of children's and adult services.***

Parents felt that the transition between school/college and adult services was not being actively managed or planned for.

➡ ***Less bureaucracy, particularly in relation to the incontinence service.***

Carers felt that direct provision by a front-line professional, such as the health visitor, had provided a better and more efficient response to their needs.

➡ ***In general, more stability in the services provided.***

Carers pointed out that they need a consistent framework of support around their own caring role. Frequent changes in the organisation and delivery of services undermine this.

➡ ***Services to be genuinely needs-led.***

Carers were highly sceptical about the extent to which service were being provided in response to need. They believed that provision was cost rather than need-driven and that many of the expenses of providing adequate care were being shifted onto the carers.

Tameside Social Services

Carers Consultation Report

June 1997

Introduction

It was recognised a long time ago that local authority services were not successfully being delivered to the Asian communities. A survey by Age Concern, started in 1987, identified firstly that Section 11 was generally seen as an easy way of addressing Minority needs and secondly, that although Service Development Workers were being appointed, the lack of appropriate support and an overall strategy meant that they had little impact.

The Black Communities Initiative work was developed to try and meet the needs of Black carers. This report gives the background to the consultation with Asian carers with a view to contributing to the development of policy and support systems for carers.

Economic and Social Context

The total population for Tameside is 221,800 and just over 4% are from the ethnic minority communities[1]. Of the ethnic minority population a potential 6,654 are Asian elderly (3% as taken from the Regional Trends 31) who are eligible for services, but in the main Social Services are not reaching them. It has been difficult to establish the actual intake and uptake by the Asian communities of services offered by the Social Service Department. This is due to the implementation of ethnic monitoring, originally planned for July 1995, not being done effectively or consistently for a variety of reasons. These reasons include a lack of awareness and lack of training in ethnicity and in the reasons why ethnic monitoring data should be collected. The monitoring of referrals was to have been undertaken since January 1996, but according to the Information Department a '60% mismatch has been found'. This lack of monitoring has resulted in a difficulty in justifying and quantifying service users' needs - an area which is recognised as requiring attention.

The Social Service Department employs 1800 staff of whom 38 are Black staff and they are employed across Adults and Children Services[2]. The Department recognises that Black staff are under-represented when compared to the proportion of the local population who are from the ethnic minority communities. However despite this recognition, Black staff are still finding it difficult to survive in an organisation which is predominantly white and whose service history, delivery approaches and planning processes are eurocentric.

The economic activity rate for ethnic minority women of working age has remained steady at 55-59% between 1984 and 1995, with a recent 5% increase in the number of Pakistani and Bangladeshi women who are economically active[3]. However by 1995, 72% of white women were economically active. At present 20,000 carers have been identified by Tameside Social Services with very few Asian carers among them. Women by default are the main carers of older relatives and neighbours and this has implications for the demands made on services in the light of community care legislation.

[1] "Multicultural Tameside", Equal Opportunities Unit, Tameside MBC

[2] The number of staff self defined as Black is 45 (Black Workers Group) whereas Departmental figures show 38.

[3] Labour Force Survey, 1984-1995

The Process and Methodology

As part of the Black Communities Initiative work, this event (in the form of a workshop) also became a launch for the work planned for supporting Asian carers. Therefore Social Services also committed themselves to supporting the Carers Impact Work at the same time.

Three Bilingual Co-Workers were offered a maximum of 10 sessions over a five week period, to speak to Asian carers either by ringing or visiting them and to invite them to the workshop with a view to collecting their views as Asian carers in relation to the Carers Impact Focus Group. As this was virtually the first time that a group of Asian carers had come together in Tameside, the process of contacting Asian carers had to be started from scratch

The workshop was a success, partly due to the Co-Workers' language skills and cultural knowledge, paired with their training in community care principles and issues which gave them quick and easy accessibility to a number of Asian carers. The availability of resources to pay Co-Workers also enabled them to put in the hard work to bring together 20 Asian carers from mixed Asian backgrounds.

Over a five week period Co-Workers identified current carers from computer data held by Social Services and introduced themselves and the work to the carers. The outreach was undertaken and food and transport were offered as incentives. In fact, if transport had not been offered, then approximately half the final compliment of carers would not have been able to attend. Direction was given to Co-Workers as they all had a different level of community work skills, and overall co-ordination of the Co-Workers was required. Originally 35 carers were identified from a mix of ages, communities and with a range of caring experiences. Each carer was visited at least twice and Co-Workers explained, using the carer's own language, about the work and the reason for calling the workshop. Confirmation letters were also sent or delivered to potential participants.

The venue was a traditionally 'white' building but it was however neutral to all attending the workshop - it was also where the local Carers Centre was based and so Asian carers attending the workshop could also see this mainstream facility and be encouraged to access it.

The afternoon started off by inviting the Asian carers to an Asian vegetarian buffet lunch. The lunch was also attended by three male service users who looked after their grandchildren whilst their wives and daughter-in-laws attended the workshop.

The workshop was attended by 2 Bangladeshi women, 5 Pakistani women (4 Pakistani men also attended but looked after the children), 9 Gujerati women and 1 Gujerati man. It was facilitated by Ashok Ohri, an Asian man using Hindi which was understood by the majority of those attending and so was a major factor in enabling the participation of ALL attending. Gujerati and Bengali speaking co-workers were at hand to simultaneously clarify and interpret.

Discussions were taped to ensure that all information was recorded. Participants were comfortable with this and it also meant that they were not threatened by the use of complicated jargon written in English.

The Workshop and its Findings

The objective of the workshop was to ascertain:

1) What needs do carers have as individuals? Are these met, either via Social Services or other ways?
2) What can Social Services do to improve the services already received?
3) To find out from carers what other kinds of services they would want in the future.

We started the workshop with introductions which also gave everyone a chance to speak in the large group.

It was explained to participants that the session would be spent first working in small groups (pairs) to reflect on the questions and flipcharting the responses. We found that this method generated a great deal of energy in the group and relaxed the participants. It lead to a high level of participation.

Out of the 20 people present, only five stated that they had received support or services from the Social Services. Given that the numbers of those receiving services was so small, the questions *"what things have helped you obtain the support you need?"* and *"what are the barriers and the opportunities?"* were abandoned. Instead participants were *asked "what services they would like to see"*. The responses are given below:

1) The Need for Information:

- More information - what is provided, eg: Meals on Wheels.
- Like to know if it is a need lead service.
- Why is there means testing?
- Is there ageism - no services are provided after a certain age.

2) Cultural and Linguistic Considerations:

- Matching should be according to need (language, availability).
- Respite care in our own home.
- Pay relatives to do the care.
- Nobody asked me "are you OK?"
- Informing people about opportunities and rights (carers feel constrained by the internalisation they feel about their personal responsibility to care as well as not seeking help).

3) Support needs:

- Carers Group for support.
- Need professional welfare rights support.
- Recognition that training is needed for people who look after the disabled and providing care centre.
- Counselling for parents with disabled children and learning needs (child psychology).
- Asian Social Worker - tend to speak in English.
- Asian Social Worker should have language classes.
- No training and support for Asian foster carers.

4) Services required:

- Ethnically sensitive elderly respite care.
- Individual assessments.
- Constraints, eg: no lift can be put in because of Council priorities.
- Need washing machine - no laundrette in the area.
- The money available is not enough for capital goods (eg: a washing machine).
- Housing applications rejected - even when supported by Social Worker.
- People still waiting for help with filling in forms.
- Day care centres.
- Need to provide facilities and services for people who are not elderly.
- No clear explanation to grandparents about child custody.
- Children need access to peer group and mixing with other children.

5) Need for a Carers Support Group:

The participants were keen to see the establishment of a Carers Support Group. They saw the objectives of the group as being:

- Equipping ourselves with rights - legal, policy and services
- Women only group - general support.
- Language and response to issues.
- Make contact with professional carers.
- Find out procedures for providing care.

The participants recognised that the Carers Support Group would need resources in order to sustain itself and to act as an advocate for the carers. The support needs for the Group were identified as:

- Transport to be provided.
- Someone to look after the children.
- Support should be there to run the group.
- The group is not ready to run itself yet.

Future action

Social Services aims to meet these carers and others again in July 1997 and to feed back their responses to the Director of Social Services along with the results of the general Carers Impact Feedback Report. It is also planed to develop a six month action plan for workers such as Lina Patel and others to take on board. The long-term aim is to offer support to Asian carers to meet together in support groups where they have control of the format, frequency and locations of meetings etc.

King's Fund
54001001323479