

Introduction

This is the final report of the City Parochial Foundation's Carer's Programme. The report aims to bring together the lessons learned through the programme, both by the funding body and by the service providers. It is a practical account of what was found to be needed by carers, and how the projects went about delivering it.

The sources for the report are the project reports and interviews with the people who worked in the projects, and the people who used the services, the carers themselves. Each chapter begins with a case study as an illustration and reminder of what is involved in caring.

Reading recently published material about carers, I am struck by how this report often echoes earlier writers. From some points of view, this is depressing: missed opportunities to develop improved local services for carers abound, even while carers have begun to win a place on the political agenda. Much of the good practice described here is still the exception rather than the rule. On the other hand the opportunity still exists. The report describes many practical strategies to improve carer support, and not all require additional resources.

The programme shows that it is possible to achieve real improvements to carers' quality of life with relatively modest levels of resources, provided that the services are flexible and responsive enough. All the evidence is that providing carers and clients with the services they want does not, as is often feared, open a floodgate of need, but rather provides a very modest level of help which enables carers to continue to care for their loved ones at home. Close attention to what carers say about their own needs is a hallmark of most of the projects; innovation, painstaking care and dedication are also evident.

The principles are not abstruse. Carers care for a person with whom they have a relationship: therefore the essence of what they need is a personal service which can respond to their needs. For instance, in the best respite schemes, where care attendants relieve the carer for a while, a relationship develops with client and carer.

The flexible approach of the most successful projects may be harder to achieve within some health and local authorities, at present providers of most existing services to carers. Since all the projects described here are in the voluntary sector, the programme sheds little direct light on this. The case study *Organising for flexible care* (page 43) shows however, that flexible does not mean unstructured. It means having a structure dictated by clients' (or in this case, carers') needs, rather than by those of the organisation. For health and local authorities it means redirecting resources to schemes which are small-scale, local, and run with slim management, effective staff support and resources concentrated on quality service delivery.

The role of central government must not be forgotten here. OPCS figures for 1990 revealed that 6.8 million people, or one person in seven adults, are carers in Britain. Of these, 1.5 million are carrying out caring duties for more than 20 hours per week, and three-quarters of a million for more than 50 hours a week. Taking the lower national figure of 1.5 million people with considerable caring responsibilities, this indicates that an average London borough would contain between 5,000 and 7,500 adults caring for more than 20 hours a week, before any adjustments for higher proportions of disabled and/or elderly people in their populations. If the higher figure of one in seven, is used for people with some degree of caring responsibility then the figure would be between 28,000 and 43,000 per London borough.

Carers' economic, as well as their caring, contribution to society has long been recognised. Yet only a fraction of carers receive service to assist them in their caring role. The increased costs of more adequate services to carers are modest indeed compared to these figures. Real improvements can be made by redirecting resources and using them more wisely, but some increase in resources is also needed¹.

Terminology

The term 'carer' is problematic in two ways. Many carers would not use this term about themselves, and may not recognise themselves when described in this way. This may be particularly true for parent carers, or carers from minority ethnic cultures where caring is conceived as a given part of an intra-family role, or an important duty. The term also raises difficulties for some of those cared for, for whom it may conjure an image of dependence at odds with their struggle to live as independent a life as possible.

Nevertheless, the term is a useful omnibus for all the kinds of people-in-relationships who make up the 'carer' population. It is also the term used by the projects whose work the report describes. It has therefore been retained but does not imply that carers are a homogenous group (which is the disadvantage of using convenient, if inaccurate, jargon).

The other major problem of terminology is what to call the people for whom the carers care. In common with the majority of the projects in the programme, the term 'clients' or 'service users'. The question of terminology raises a more profound issue: that of the differences between, as well as the common, interests of clients and their carers.

¹ Warner, Norman, Better Tomorrows, Carers National Association, 1995.

The Programme

Initial steps

Between the end of 1992 and the beginning of 1997 the City Parochial Foundation (CPF) gave £1.5m to 11 voluntary sector carers' projects throughout Greater London. The Trustees' decision to allocate these funds was influenced by its regular review of priorities every five years; a review of grant-giving for the years 1987-1991 had identified gaps, particularly in work with carers, mental health and penal affairs. Programmes were initiated in each of these areas, and this is one of three major reports on the schemes.

A first step had been taken in 1991 by funding a researcher, Marlene Winfield, to undertake the Four Boroughs Project, which analysed the needs of 300 carers, and the extent to which those needs were met, in four West London boroughs. The main findings of the report were:

- 1 The majority of carers wanted only modest support to enable them to keep on caring, but many were not receiving it
- 2 Awareness was very low among carers of the statutory duties of social services departments towards them, resulting in failure to meet even emergency needs
- 3 Health care providers, including GPs, failed carers through inflexibility, and lack of knowledge about services for carers
- 4 Written information about services was poorly distributed, largely unavailable in languages other than English and assumed too much knowledge on the part of the carer
- 5 Services were consistently under-used by minority ethnic carers, leading to unplanned and piecemeal development of separate services, rather than making mainstream services accessible
- 6 There was a general failure to involve carers in planning and decision-making, and only token involvement of the voluntary sector in drawing up Community Care Plans
- 7 The researcher expressed doubt about whether any of the four social service departments would be able to implement the NHS & Community Care Act within available resources.

The gap between need and existing services, both in quality and quantity, was so great, that the CPF Trustees were then concerned about how much difference could be made with £500,000 a year for three years. Rather than simply announcing the terms of the funding and waiting for applications to arrive, they decided to adopt a pro-active approach, and to focus resources to achieve a real difference for relatively modest numbers of people, rather than spread funds too thinly across the whole of London.

The concept 'carer' was felt to be still too broad. The low take up of services by carers from minority ethnic communities made the Foundation particularly anxious to fund projects which could contact these carers and begin to meet their needs. After a consultation exercise with experts in the field the Trustees, agreed a more focused set of priorities, as shown below. The Foundation sent information about the criteria and the application process to 250 Carers groups, together with an invitation to an initial meeting to discuss practicalities: over 100 attended.

Programme objectives

- 1 The development of comprehensive and imaginative respite care.
- 2 The development of appropriate and sensitive information and advice for carers, to improve access to services.
- 3 Developmental and strategic work with carers, either locally or across London, to help voluntary and statutory services tackle:
 - Better Equal Opportunities provision
 - Training for people working with carers
 - Inter-service collaboration to enhance service delivery.
- 4 Developmental work with minority ethnic communities to establish links with existing services.
- 5 Work with carers of people who are mentally ill within Black and minority ethnic communities.

Rather to the surprise of staff, there was no overwhelming flood of applications: only 44 in all. Eventually there were 12 final applications, of which nine were fully funded from the outset and three were funded for feasibility studies and of these, two later made successful funding bids. Five of the eleven projects funded were

based in the four boroughs where the preliminary research and development work was undertaken. This 'coincidence' underlines the importance of the pro-active approach as even a well-publicised opportunity for funding will not necessarily evoke a dramatic response. The high success rate of applications, however, probably also indicates a better than average rate of self-selection.

It had always been stressed that resources would be focused on a small number of projects, and that the aim was to provide not only additional services, but also lessons for statutory and voluntary service providers, and for funding bodies.

Forum and monitoring processes

There was a strong emphasis on monitoring. In addition to regular project reports and bi-annual monitoring visits, there was throughout the programme a six monthly meeting of all programme projects which became an important source of intelligence, ideas and support.

This forum meeting was a key tool for the funders' continued involvement with the projects, as well as an important opportunity for the projects to be involved with each other through exchanging information, sharing of ideas and open discussions. This allowed learning between projects and informal monitoring of progress. The meeting gave funders and projects alike an overview of the programme; the Foundation gained a much clearer sense of how they were meeting their objectives through the funding, and developed an effective partnership with providers.

Lessons for funders

Objectives for specific projects were arrived at by a process of negotiation at the outset, and Foundation staff found this helpful. An important lesson for the funders was that it was best to be relatively demanding with the projects at the outset, in requiring clear objectives or challenging unrealistic targets, to give projects clear messages about what was expected before the funding commitment was made. It was felt too that funders' expectations were realistic: not every project in a programme needs be outstanding.

Planning and review processes were also built in from the outset. Monitoring information collected by the funder was sometimes returned to the projects for use in funding bids to other bodies.

Once the funding was given, the funder was committed. The staff role shifted from assessing the project's capacity to achieve its objectives, to supporting it in achieving them. Staff emphasised the importance of projects being open about difficulties, and they themselves exercised forbearance and offered practical aid. To help projects resolve difficulties, additional support, such as consultancy, was given in several cases, for example around equal opportunity policies. None of the funded projects closed during the three year period of the programme.

Because the terms of the programme funding required a closer relationship than usual between the funder and funded bodies, staff commented that the process offered them opportunities to learn that do not exist in 'ordinary' funding, for instance, coming to grips with the unpredictable time demands of developmental work. More than one member of staff commented on how often an intuitive judgement about projects was borne out by subsequent experience, particularly in the case of projects which developed excellent practice.

It was also much harder at the end of the funding period to leave projects to fend for themselves; in ending funding, the process was one of discussion, not fiat. In some cases underspend from earlier years, or small additional sums, were used as transitional funding while other applications were made. In the event most of the projects in the programme gained ongoing funding, via the local or health authorities, other charitable trusts, the National Lottery or a further grant from the Foundation itself.

Staff felt that the programme, offering 100% funding, was appropriate for projects undertaking new work as the question of funding funds can be set aside for a while, allowing the project to concentrate on its practice innovations. The flexibility needed by carers had to be recognised, as new approaches sometimes work well, and sometimes do not, so it may take longer to 'get it right'.

Despite the clear benefits to projects of guaranteeing funding for three years, the closer involvement in the work of the projects convinced some officers of the Foundation that three year funding for developmental work was no long enough. In some cases it took the projects a year to start up, leaving only 12-18 months for developmental work. In many cases the work began to bear fruit in the third year of operation - just as the question of renewing funding again assumed a priority. Much of the work undertaken relied on the long-term fostering of relationships, with carers and with professionals, which are likely to take longer than a year to achieve.

Five years may well be a more useful funding period for most of the kinds of innovative work in which the projects were involved; for work of particular difficulty, for instance where considerable effort is needed to contact and develop relationships with very isolated minority ethnic groups, even longer may be necessary.

The focused nature of the programme provided a particular opportunity to understand the needs of carers in depth as well as in breadth, and at the same time uncovered a disturbing level of unmet need. Services are not reaching London carers, and are least effective in reaching those carers who need them most. Sometimes the reports of projects left the funder with a sense of 'barely scratching the surface'.

Nevertheless there was a sense of making a small but real contribution to a great area of unmet need, and a sense of effective partnership with the service providers. In eight boroughs, much better services for carers were developed, with evidence that the work will continue. This would not have happened without the programme.

Lessons for funders from the programme:

- Be tough on objectives at the outset - are they clear and realistic?
- Build in communication and monitoring from the outset
- Encourage openness, and give support in overcoming difficulties
- Closer contact increases funding staff's learning
- Projects were supported in finding further funding elsewhere; most succeeded
- 100% funding is appropriate for innovative work
- Five years may well be a more appropriate period than three years when funding developmental work
- There are disturbing levels of unmet need among London carers
- This was an effective partnership with projects in meeting previously unmet need.

The Projects

There has been a number of important lessons from the work of the projects. Rather than create a repetitive text which deals with each project in turn, these lessons are structured thematically in the following three chapters. In this chapter there is a brief summary of the work of each project, and where issues or achievements of particular interest are mentioned an indication is given where else in the report further information is provided.

Six schemes (Age Concern Enfield, Brent Triangle, Crossroads in Enfield, Harrow and Sutton and the Chinese Health Resource Centre), aimed to provide domiciliary care to allow carers a break. Six (Age Concern Wandsworth, the Chinese Health Resource Centre, Contact-a-Family South West London Region, Carers Support Brent, Carers in Ealing and Hillingdon Carers) were concerned with providing support, information and advocacy services.

Three projects (Age Concern Wandsworth, the Chinese Health Resource Centre, Hillingdon Carers) were focused exclusively on people from minority ethnic communities. Two others (Carers Support Brent and Harrow Crossroads) had posts focusing on the needs of Asian carers. Most projects operated within a single borough, except for the Chinese Health Resource Centre, and Contact-a-Family, which focused on the three boroughs of Richmond, Hounslow and Kingston.

Most of the project were schemes set up by established organisations. The exceptions were Carers Support Brent and Carers in Ealing, plus a consortium in North East London which did not proceed beyond the feasibility study. There were three local Crossroads schemes in the programme, two local Age Concerns, and several organisations affiliated to the Carers National Association. All had local management committees or advisory groups, and one (Carers in Ealing) developed a committee composed only of carers and ex-carers.

The first project to be operating under the scheme was Brent Triangle in December 1992; the last was Age Concern Enfield, starting in late 1994. Alongside the name of each project is shown the amount of funding given for the full three year period.

All the projects recorded a considerable amount of information during the course of the programme. All made an impact. Carers and clients benefited. For the Foundation the investment in terms of money, time and effort was more than justified. The projects are continuing and in many cases permanent services have now been established. Other funders who have followed on the Foundation's grants have been convinced by the outcomes that these services are value, not solely in terms of unit costs but also by the imaginative and humane response to carers' needs. Informed judgements can be made about what costs would be incurred were such services not in place but there is no neat causal proof. Those seeking detailed information from any of the funded projects can contact them at the addresses listed at the end of the report. Within this report brief examples of outcomes of the work are given with each of the eleven projects summarised below.

Age Concern Enfield (ACE)**£68,478**

The project was established within a local Age Concern branch, aiming to relieve stress on carers with the provision of a home-based respite care service which allowed carers of older people, in the main older people themselves, to take a one-week break from the carers role. Initial difficulties in recruiting staff led to a delay in setting up the project.

“A great idea -- but not for me” summed up the response the new project coordinator encountered to the offer of a week's respite care. What the carers overwhelmingly wanted was a much briefer, but more regular period of relief, such as an afternoon every week or a day every fortnight. The project responded by providing carers with what they wanted. As confidence grew in the quality of the care provided, some carers began to accept longer periods of respite, going away for two or three days, or even for a whole week. The majority of the clients cared for have dementia.

The project developed a relaxed and welcoming style which was a strength in making contact with carers, for whom the process of joining was made as easy and informal as possible. Carers are encouraged to explore what they want from the service. Word of mouth contacts, and persistent visits to relevant agencies, such as an Asian Day Centre, reaped results. Care attendants met monthly for support and supervision, and at least one of three full-time staff were available to them in an emergency.

The service recruited a bank of 25 people offering home respite ranging in age from 20 to 64 and offering four minority languages.

Age Concern Wandsworth (ACW)**£117,986**

Based in Balham/Tooting, this access project set out to provide support for Asian carers. It started with a period of outreach in order to become accepted within the Asian communities. This included visiting Gurdwaras, Mosques, Temples, Churches; stalls in shopping centres and cultural centres; publicity through TV Asia and the Asian press; speaking to Asian shopkeepers to identify informal clubs and meeting places, and following up personal contacts. A generally low level of cultural awareness among professionals spurred joint work with hospital link workers, social workers and district nurses. At first there were no referrals from statutory organisations; after three years there were many.

With a clear focus on Asian communities, there were few preconceptions about what the service should be; rather an invitation to Asian carers to talk about their needs. It soon became clear that it was very hard to separate the needs of the carer from the needs of the client and of the family in general. Contacts were made with many Asian carers who were socially isolated, and the worker spent much time giving one-to-one support, or giving advice and information about health and social services, benefits or housing problems. Almost all the carer families contacted were receiving less benefit than their entitlement. After three years, this remains true of new clients. The project continues to work with local professionals.

There were few appropriate respite services available, and no home-based service, which was what most Asian carers wanted. They did not necessarily wish to go out while the care attendant was there, but wanted a companion, either for themselves or for the person cared for. Some people wanted a companion who would take them to Temple or to the shops. There was no local respite scheme, and attempts to set up a volunteer-based scheme within the project had only limited success. Issues raised by the project's work are discussed later in this report.

The project, like that in Hillingdon, has been successful in making and maintaining contact with Asian carers, and has reaped some of the same consequences of success. The Tudor Trust has guaranteed funding for two years, and further applications to the local authority are being made.

The original plan was to identify approximately 40 carers over three years. The Project exceeded these expectations. Within two years of them being operational - the Project identified and made its own assessments of 50 carers, identifying an alarming need within the community.

Thirty-two of the carers were over 55 years old. Eighteen of carers were between 25-55 years old and having caring responsibilities of their elderly parents or in-laws.

Brent Triangle (BT)

£103,954

Brent Triangle was an established agency providing day-time care at home for people suffering from dementia, usually as a result of Alzheimers Disease, or from other mental illnesses. The CPF funded project was to establish in addition a new night relief and support service to carers of elderly mentally ill people, up to two nights per week per carer.

Originally set up as a separate scheme within the organisation, the project discovered that it made more sense to integrate it with the day-time scheme. BT is especially successful at recruiting and retaining committed and effective care attendants. It does this by demonstrating the same commitment to supporting its staff that it expects the staff to show towards its clients. It was singled out in a Social Services Inspectorate report on Brent services as offering a model of excellent practice:

“Services provided by Brent Triangle were particularly highly commended for their flexibility, reliability and professionalism in supporting carers of people with dementia. The quality of that service was enhanced by the consistency of staff going into the home, and by those care staff undertaking all the tasks that were needed by that household. A reflection of the satisfaction with that service was the high degree of trust which carers expressed in Triangle, and the confidence they felt in receiving respite care from them”.

More information about its approach to staffing is given in the case study on page 43. BT has been funded to continue its night service by the National Lottery, and has also attracted increased funding from the local social services department, both in contracts and on a case-by-case basis.

Between April 1993 and July 1995 14 clients were provided with ‘care hours’ for a total of 524 nights and 6,086 hours. The night care attendants are contracted to work on a 20 hour rota per week. This was generally exceeded by two to four hours a week. The average age of the client was 80. There is a waiting list of 18.

Carers in Ealing (CIE)

£137,106

Another new project, CIE began as a daughter project of the local Council for Voluntary Service, to set up and support a representative borough-wide forum for all carers of adults between the ages of 19-59 years. Originally granted funds for a feasibility study, the project was confirmed with three-year funding. During the feasibility study year, the upper age limit was abandoned, as unnecessarily restrictive with an ageing local population. A survey of local carers was conducted, and a broader approach to representing carers was adopted.

Contact with members was maintained through a regular newsletter, and through forum meetings which also have a support function. The project is rare in having a management committee consisting wholly of carers or ex-carers, which carried out much of the role originally envisaged for the forum. Liaison with social services and other local providers was shared between staff and committee members, and carers' issues are now firmly on the local political agenda.

CIE organised an effective one-to-one telephone support network, which is underpinned by regular social events. The project has been particularly successful in contacting and supporting Asian women carers, and runs an informal support group in the local Gurdwara, the culmination of many months' patient development work.

More lessons from the project's work may be found in the later sections. Joint funding for some project work has now been given by the health and local authorities.

During its third year the project consolidated its position locally and is now widely recognised as being the predominate carers organisation. The project has more than 300 carers on the mailing list and three paid staff.

Carers Support Brent (CSB)

£123,690

This was a new project, established to provide a key point of contact in Brent for carers of people of all ages and disabilities. It aimed to provide information, advocacy and assessment services to carers; to work with local GPs; to develop a multi-ethnic volunteer force; and to enable carers to play an active role in community care planning.

A project with a particular strength in publicising its services, CSB again demonstrates the merits of a highly planned proactive approach. Through large-scale mailing, outreach stalls, and contacting carers via professionals, it reached hundreds of carers. It maintains contact with around 400 through a regular newsletter.

The project also offered information, advice and support over the telephone, and employed staff who speak most of the major Asian languages spoken in the borough. Home visits were sometimes offered, but resources severely limited this. CSB ran support groups, and established a new method of working with GP practices which

looked set to uncover many more hidden carers. It facilitated the involvement of carers in community care planning through a carers' forum which fed into the complex structures of policy formulation. The Princess Royal Trust for Carers has provided future funding for this project, with a further £30,000 over two years from the Foundation to help develop a Carers Forum.

In its first 15 months 501 people contacted the carer support and information line of whom 42 per cent were from the ethnic minority communities.

Contact-a-Family (CaF) South West London Regional Office

£195,627

Here CPF funding established a regional branch of a national organisation which provides information and support to parents of children with special needs. CaF SW London, which covered Kingston, Richmond and Hounslow, had a particular brief to work with parents from minority ethnic communities. It also had a highly strategic and planned approach to its task, always mindful of the limits of three-year funding; it is now in its final stages, aiming to consolidate its earlier work, and to replace the paid staff with volunteer representatives in each borough.

The project has achieved a great deal in its limited span, often working with partners such as the Indian Workers Association, or local Health Visitors, to help maximise the impact and durability of its work. It has aimed to provide information for parents and professionals, particularly through one-off workshops bringing both sides together. It has provided fun one-off events for families, and in one of its three boroughs produced an information guide which was so popular that supplies of the first print ran out within weeks. It works closely with, and aims to influence the practice of service providers, often through policy forums.

Parent users spoke highly of the project, and commented that it had a positive impact on the services they receive from professionals. More information is given in the case studies on pages 54 and 56. Parents would it clear to CaF that the regional office will be missed, The Foundation provided a reduced grant of £41,000 over a second three year period with five other trusts contributing £60,000 to enable the work to continue.

It established five new support groups and strengthened eight others; contacted 518 families; worked with 28 Asian families in Hounslow and in one year dealt with 268 enquiries requesting advice on rare

Crossroads Enfield (CE)**£141,350**

As an established scheme providing day-time home care attendants, CE was able, through CPF funding, to establish a night care service for carers of anyone with a severely disturbed sleep pattern. In practice the scheme, limited to a maximum of one night a week, is used mainly by two groups: those who care for people with dementia, and those who care for young people or children with disabilities.

While in some ways an extension of the existing scheme, the night service proved harder to “sell” to carers than initially anticipated. About half the scheme’s users used it for only one to two months, waiting until they could not do without it, often when the cared-for person is near death, or could not continue to be cared for at home.

In common with Brent Triangle, the other scheme offering a night service, CE found that listening and offering support to the carer was as much a part of the care attendant's role as was caring for the client. This led to an extension of the hours through which the scheme was available, and a determination to ensure that the same care attendant works with the same family.

Continuation of the scheme has been achieved with local authority funding; there has also been a growth in case-by-case funding.

In its third year it provided 4,498 night care hours for 39 carers, of whom one third were self-referrals. Eighteen of the carers and 29 of the cared for were over 70 years of age.

Harrow Crossroads (HC)**£160,000**

Harrow Crossroads was set up with CPF funds plus joint funding from health and local authorities. It aimed to provide carers with short-term relief from the caring role by providing home-based care attendants. CPF also funded a full-time equivalent post doing outreach work to help hidden carers access the service, and to set up and run carers’ support groups. The post was divided between a general access worker, and a worker whose role is to encourage access by Harrow’s Asian communities.

The project was successful in contacting carers via local hospitals and information days, and in setting up and running carers’ support groups, with four or five groups currently running. One of these was based round a GP practice, and two were for Asian carers. With some Asian carers a more informal one-to-one support setup was more effective.

Most of the clients cared for by the Crossroads service are now older people or children with disabilities. Statistics suggest that use of the service by Asian carers is now proportionate to the numbers of Asian people in the borough. Staff highlight the low use among clients aged 16-60, where there is in any case a low base of services. The project will continue albeit, at a reduced level, with resources from local joint funding and a further £30,000 over three years from the Foundation.

Harrow Crossroads has six staff and 17 core attendants. A total of 300 care hours is provided each week. In 1996 280 carers situations were assessed. Of the current 277 carers being supported 192 are female, 165 are over 60, 149 are spouses and 36 are from the Asian community, compared with seven in 1994. The majority of services are provided weekly. Of the 257 being cared for half are female, the vast majority are over 60 (including 26 who are over 90). The most common disabilities are as a result of Alzheimers, stroke and frailty.

Hillingdon Carers (HC)

£152,729

The CPF-funded project was to provide access for Hillingdon's Asian communities to the HC information and advice service already available to English-speaking carers. It also had a role in identifying unmet needs and possible ways of addressing them.

The project was staffed by two outreach workers and a part-time administrator, speaking between them the five main Asian languages used in the borough: Punjabi, Urdu, Gujarati, Hindi and Bengali. The staff were successful in contacting hundreds of Asian carers through outreach in hospitals and shops, training days and other joint initiatives, as well as via religious events and community networks.

Bengali-speaking people in the borough were, in practice, much more difficult to contact and tended to have greater needs, than other Asian communities. The Bengali worker, who was part-time, worked exclusively with Bengalis while the full-time staff member dealt with other groups. Religion was also important: as a Muslim, the part-time worker was successful in contacting devout Muslim Bengalis; similarly, the full-time worker was particularly effective in contacts made through the Gurdwara.

Both of these staff combined outreach with information and advice work, and towards the end of the CPF funding are reaping some of the problems of success: they have increased carers' expectations to the point where the demand on them for information, advice, support and advocacy took up most of their capacity. The organisation has responded by allocating more staff time to direct work with Asian carers. Staff have also developed a good relationship with the local social services department, resulting in referrals of people who have been assessed. At policy level too, HC is regularly consulted about carers' interests. In forming a new management committee, the organisation succeeded in recruiting almost half its Trustees from among Asian carers, who thus have a voice in the future of the organisation as a whole.

The key unmet need of Asian carers was identified as appropriate respite care, either residential or domiciliary. The project has gained continued part-funding from the local authority and a final two year grant of £34,000 from the Foundation.

The initial aims of outreaching to the community was achieved. There is a current case load of 125 Carers registered with the project (increasing by approximately 20% per year) who require ongoing support. There are 250 ad hoc enquiries a year from carers as and when they need advice, information and support.

London Chinese Health Resource Centre (LCHRC) £88,390

LCHRC used its feasibility study funding to set up an action research project, linking with a small number of Chinese people across London. The service was aimed at all Chinese carers. Because Chinese people tend to be dispersed, often working in the catering trade, isolation and lack of support can be a severe problem, as can the language barrier in negotiating with statutory service providers.

The project achieved a cooperative and robust working relationship with social services departments, particularly in its home borough of Westminster. In addition to offering support, advocacy and information, the project began to meet a strongly felt need for respite care, using Chinese students as care attendants. The three year project continued along similar lines.

LCHRC was aware of a considerable unmet need among Chinese carers in London, and successfully applied to the Department of Health to continue its work with carers. Its experience offers valuable insight into effective ways of contacting Chinese carers.

Training courses were provided for carers and for local authority staff. A core group of 13 Chinese/Vietnamese carers and dependants received support and advice.

Sutton Crossroads (SC)

£83,178

This project began with the aim of piloting a flexible home-based holiday respite scheme for carers of people with physical disabilities. As with Age Concern Enfield, it soon learned that a weeks respite for a holiday was not at the top of most carers' priority needs list. Most carers preferred, initially at least, to have a short regular break; after a time they were increasingly prepared to go away for longer.

The project decided to offer a very flexible scheme, with a maximum of two weeks per carer per year, although it was prepared to offer longer periods to those who are travelling long distances, such as Asian or African-Caribbean people visiting family abroad. The style of use up to the maximum is wholly determined by the carer. Some carers are offered 'cancellations' in addition to their allotment. The scheme received an increasing number of requests for crisis care, such as when the carer become ill and has to go into hospital, and has now been extended to cover people caring for those with dementia.

Initial problems in recruiting care staff were overcome with a more relaxed and informal style of recruitment, with the requirement that prospective attendants be only caring, responsible and reliable. A rich bank of talent has emerged among the care attendants, who include trainee music therapists, medical and psychology students. A supportive management committee has been important in the success of this project, which has obtained continuing funding from the National Lottery Charities Board.

In its first full operational year the service provided 40 weeks of respite for 28 carers of whom 24 were female and 17 over 60; 18 of the cared for were over 80.

Carers' Needs and Project Responses

This chapter presents four case studies (no real names are used) which illustrate carers' lives, and then discusses some of the main needs of carers. It goes on to introduce some of the work the projects have done to address those needs. The content is mainly based on conversations with carers, but also reflects the comments of project staff, and a survey of 152 carers conducted in 1994 by Carers in Ealing.

Tom and Aileen

Tom cared for his wife Aileen, who had Alzheimer's Disease; they had been married since 1946, and when first in contact with the respite scheme were 72 and 76 respectively. "The first thing you notice", he said, "Is that things are missing and turning up in odd places. I was sure something wasn't right when her handbag showed up in the fridge". Aileen became withdrawn, not joining in conversation with family and friends. Even more distressing were the violent outbursts which were so untypical of her.

Despite little sleep from nights of enforced wakefulness, Tom was determined to care for Aileen himself. "No one can understand her like me". He didn't want to accept respite care, because he felt it unsuitable for someone of an active disposition. "They don't talk to them or do activities, it's just physical care. She'd get bored and go wandering".

Tom and Aileen had one son and two daughters living fairly close, as well as another son in Germany. They all found visits very upsetting, and didn't offer much practical help to Tom. "After all, they have families of their own," he said. "Not much time to spare".

He learned of the new home respite scheme when the organiser contacted him at Aileen's day centre. Soon after, increasingly desperate for a break, he agreed to try the scheme. "I was very impressed by the list of questions they asked me. Everything from where the gas tap and mains switches are to what Aileen likes to eat and do. The first time Anna (the care attendant) came, Aileen really enjoyed looking through old photos with her. Soon they were thinking of new things she would enjoy. I began to see the respite as something for Aileen as well as for me!" Gradually Aileen would even allow Anna to wash and dress her, which she sometimes wouldn't let Tom do.

As time went on, Tom felt able to go away for longer, and as well as his weekly break which allowed him to keep up with old friends, he accepted a week's respite. He went to Germany to see his son and family, meeting one of his granddaughters for the first time. Aileen gradually needed more physical care, becoming doubly incontinent and finding it hard to move about. Her behaviour was still erratic. She needed to be lifted from bed or her chair, and Tom, increasingly frail himself, found it hard. During the day, with home help and district nurse coming in, he could cope. At night however, it was very difficult. He learned that the respite project could offer him a care attendant for up to two nights a week, allowing him to catch up on sleep. Tom was unsure about introducing new people to Aileen, but it turned out that Anna could come at night as well as during the day. She came most of the time, and when she could not, Cathy, whom Aileen already knew, was the back-up attendant.

Getting two good night's sleep a week made a lot of difference to Tom, as did the chance to talk to Anna, whom he liked. Aileen's behaviour was getting worse though, and continued to place Tom under strain; physically she required more and more care. His own health deteriorating, Tom was persuaded by his daughter to think about placing Aileen in a residential home. The care attendants, particularly Anna, supported Tom as he made the difficult decision, even visiting him a couple of times after Aileen's admission to the care home. Despite his sadness, Tom was proud that he had managed to cope for so long. Aileen died peacefully six months later, Tom at her side.

Sung Family

The Sung family worked in the restaurant trade and had good links with the local Chinese community. Neither Mr or Mrs Sung spoke English. When their only son Chang was thirteen, Mrs Sung had another baby, Li. With hindsight, the Sungs realise that Chang's difficulties began then. Chang was extremely jealous of his brother, and his behaviour to his parents became very hostile. The family hoped to resolve the problem themselves, and didn't seek help until they were desperate, after Chang had begun to punch and kick his mother.

Chang's behaviour was improved somewhat by drugs, and the family were allocated a Chinese social worker, until local authority cuts meant that she had to leave. Chang then waited six months to enter hospital for treatment. The hospital had a good reputation, so the family were very angry when he was sent home after ten days because he couldn't fit in. "If he could fit in, he wouldn't need to go there," said his father. The family did not learn that they could complain about the hospital until much later.

The family did not want to let their Chinese friends know about Chang's illness, because of the fear and stigma attached to mental illness. They therefore had little support and were struggling to keep the restaurant running and look after Chang at the same time. They faced another long wait for treatment, finding it difficult to understand the 'system'; Li was very scared of Chang, and Mrs Sung was again pregnant. They were at the end of their tether. It was at this time that the family first learned about the Chinese project which helped Chinese people caring for someone at home.

The project offered the family a care attendant for several hours every week, to help them keep their business going, accompany them to hospital and translate when necessary. Acting as an advocate, a staff member helped the family get treatment for Chang at a second hospital, nearer home, which was much more successful. On another occasion they helped get a reduction in drug dosage when Chang experienced bad side effects. What was perhaps even more important was the information given about Chang's condition, so that the family realised it was not their fault that he was ill, and that recovery was possible. Chang was by this time a young adult, and staff built a relationship with him, encouraging him to volunteer at the project.

Though still jealous of his brothers and occasionally hostile, Chang has greatly improved and is now living in his own accommodation. His parents continue to run the restaurant and bring up their younger children.

Maria and Conchita

Maria looks after her daughter, Conchita, who has severe learning and physical disabilities, and cannot speak. Maria has been a single parent since her husband left, three years after Conchita was born. Conchita is now 18. Maria had little support from family or community, as Conchita's disability was felt to be her fault. Conchita is an active girl and Maria does her best to arrange the activities she enjoys most, especially music and sport.

Two years ago, Maria had come across the service for parents of children with disabilities. She is enthusiastic about it, particularly about the borough guide they have produced: "The change has been tremendous." Maria now feels she has the important information she needs, particularly to help in choosing an adult centre for Conchita. "There is going to be a new centre, with music therapy and art, where they have the sign language Conchita uses to communicate. The centre also offers short-term respite, and sports clubs."

She has recently acquired a car, and so is now able to take Conchita to a nearby town for swimming lessons reserved for girls with learning difficulties where her behaviour will be understood. When asked about what happened before she found the information service (when Conchita was 16), she comments, "There was nowhere I could take her."

Maria had found that life caring for a severely disabled child was full of obstacles and barriers. "I had unnecessary trouble. I once spent a whole day on the phone just finding out where to get her shoes repaired. It was very hard, finding the school myself. That is another thing that has changed. The professionals' attitude is better. I used to get so upset and then so angry, because they would always talk down to you, and what you said was discounted, unimportant -- they were the experts. Now some of them at least have learned to listen to us parents, they treat us with more respect. I think it is because of the workshops the project has run, where they mix with parents on an equal basis. And Mary and Carol at the project will always listen if you need to talk. Sometimes it is all you need, to talk to one person who understands and respects you and what you are trying to do. Then you don't feel quite so alone."

Farida and Mohammed

Farida had come from Pakistan to marry her husband, Mohammed, who was some years older than her. She spoke no English, and Mohammed said that she didn't need to learn, as she had him to do the talking in English. She was now in her late twenties, with five children aged between three and eleven. Her husband had suffered an accident at the age of 42 and as a result was paralysed and lost the ability to speak. This made him very frustrated, and sometimes withdrawn. "He was always such a good man," she said, "But now he gets so angry, and it can't come out."

The family had a visit from social services, but it was not much help because they sent an Asian social worker who did not speak Bengali, the only language Farida speaks. They have had no adaptations done to their house, and have only coped by moving Mohammed into the downstairs sitting room, and getting a wheelchair and a commode from the hospital. He has been offered no physiotherapy nor occupational therapy. He did go to a day centre for two days, but made it clear that he did not want to go back. The food was not suitable for him, and there was nowhere he could go to pray. Mohammed is a devout Muslim, and Farida changes his clothes completely five times a day, in order for him to pray. The new clothes must be freshly laundered. The accident has left him doubly incontinent, so there may be additional changes if Farida does not succeed in getting him into the toilet in time. He will not use incontinence pads. Farida has no washing machine, and does all the washing, for herself, Mohammed and her children, by hand in the kitchen sink. "I spend a lot of my time washing," she says.

The worker from the Asian Carers' Access Project first contacted Farida when she goes to collect Mohammed from the Mosque. She visits Farida at home, and asks her how she copes and what help she needs. She offers to check that Farida is getting all the benefits she should be; Farida readily agrees, as money is very tight. The worker calculates that Farida is entitled to about £45.00 per week more than she is getting! She helps Farida fill in the forms. She adds that if there is any problem about the claim, she will deal with the Department of Social Security on Farida's behalf. She also helps Farida to apply for money for a washing machine, and tells her about several kinds of help she could be getting from the Social Services department. For instance, there is a new Muslim-run respite centre in a neighbouring borough, where Mohammed could go for a while to give Farida a break. Farida doesn't see the point of this: "Where would I go?" she says. "I have to look after my children anyway," but she is keen on the idea of a visitor coming to sit with Mohammed for one or two mornings a week. "Then I could do my shopping with peace of mind." The access worker promises to arrange this.

Three principles for providing services to carers

All the carers in the case studies care for people who are important to them. Their situations and needs are widely different, and change over time; the needs of the person cared for may also change. For this reason, rigid or standardised services are too crude to be appropriate. The first principle in providing services to carers is that to be useful, the services must be flexible and able to accommodate changing individual needs.

The second principle is that carers' services must be accessible. In two of the case studies the fact that the carers spoke no English exacerbated the difficulty of getting services; the absence of services which can meet specific cultural requirements (such as those a strict Muslim, needs) means that carers who already get little help are effectively debarred even from what is available. The onus for accessibility lies with the service provider, not with the carer or client. For instance, the practice, still widespread, of using clients' children as interpreters, is an evasion of the service providers' responsibility towards clients. To be accessible, especially to carers from relatively small communities, services must also maintain strict confidentiality.

Services for carers must be:

- Flexible
- Accessible
- Caring.

The final principle is that the services must be delivered in a personal and supportive way. One of the key issues for many carers is the social isolation which results from their devotion to the caring role. The projects all tended to recruit people with a strong caring orientation, and this was important to their success. Carers using the projects repeatedly said how important it was that staff were caring and would listen to them. "They always have time for you", "Just to know that someone understands", "I just need to let off steam sometimes" were frequent comments.

In the night care scheme where clients were dementia patients, the time allocated for a normal session was extended by two hours because that was the average amount of time that the carer spent "just talking" to the care attendant when s/he arrived. After this period of winding down, the carer was able to hand over her/his responsibility and get a good night's sleep. It was recognised that this informal support was part of what made the service valuable to the carer.

An important aspect of caring is that it includes the idea of reliability. At the risk of stating the obvious, services for carers must be reliable. It is a big enough step for carers to accept help, especially help with their caring responsibilities. When they do so, it must be help they can rely on. A carer who has expected help and been disappointed, is in a worse situation than one who has never expected help.

Three kinds of services carers need

Carers need:

- Information, advice and advocacy
- Support and a 'listening ear'
- A regular break from caring responsibilities, and the chance of an occasional longer break.

Information, advice and advocacy

A major problem for carers is learning about and actually receiving the statutory assistance for which they are eligible. For example, many are not offered aids and adaptations, respite or day care places, unless they press their case; similarly, many carers, particularly those who do not understand English, are receiving less state benefit than their entitlement. Information and advice services are therefore vital; most of the projects' staff regularly take on the role of advocate with the statutory service providers on behalf of carers, even where information and advice is not the primary role of the project.

Some groups of carers tend to have higher information needs than others. Those who do not speak English are one such group. So are the parents of disabled children, who have to find their way through several bureaucratic mazes in their quest to secure adequate services for their children.

Ways of informing carers are:

- Information days and workshops
- Conferences on key issues
- Discussion groups
- Publicity stalls

- Visiting community and religious groups
- Communicating via cooperative professionals
- One-to-one information, advice and advocacy
- Newsletters
- Leaflets and posters
- Guide to local services for carers and clients.

Support

Support is a very personal matter, and seems to work best when it is informal in style, even if it happens with a formal structure such as a support group. The awareness that others face the same issues can be supportive in itself, so support may also often occur as a by-product of activities with another main aim, such as information days or social events.

Ways of supporting carers are:

- Project staff being available by telephone 'as and when'
- Structured telephone helpline provision
- Allocating care attendant time each visit to listen to and support the carer
- Providing telephone networks for mutual support, matching carers with each other
- Providing one-to-one support by project staff
- Matching carers to provide one-to-one support based on mutual needs or interests
- Providing informal discussion groups
- Providing support groups
- Providing social groups of carers
- Running 'time for you' days for carers, with relaxation, aromatherapy, massage.

Carers of people whose behaviour is challenging or distressing, or where personality has changed, in general have higher support needs. The daily pressure of dealing with a dementia sufferer, or a child or young adult with challenging behaviour, puts great stress on the carer. Where the carer is a parent, there are often also feelings of guilt or responsibility for the child's behaviour. This is another reason why information events can be experienced as supportive: better information at least reduces or dispels the guilt.

Regular breaks

A regular break from caring to recharge the batteries, have some time to oneself and gain the strength to continue caring, is crucial to carers. It is consistently cited as the help that carers most want, and this is borne out by project staff's experience. Having said that, carers vary widely in their needs for respite, and in the opportunities open to them in the time they have available. The needs of a couple with one severely disabled child and two other children, and those of a non-English-speaking elderly Asian woman caring for her husband, may be very different. In the first case the need may be to spend time with each other or with their other children. In the second case, the need may be for a companion to take the carer and the client to worship, or to the shops.

Helping carers get a break can be achieved by:

- Care attendant caring for client at home, during the day, at night, or over a period
- Building up carers' trust in care attendants and project staff
- Care attendants developing a relationship with the client as well as providing care
- Offering the opportunity for a longer break
- Organising carers' social and/or information events, with care for clients built in
- Care attendant taking client to day care
- Culturally appropriate care options
- Care attendant taking carer and client to hospital, shops or religious centre
- Organising short stay places, and providing back-up so carer

- Assisting the carer in exploring care options
- Befriending schemes
- Family care schemes, with good quality selection and training
- Holidays for the cared for
- Holidays for both accompanied by an extra carer.

Hidden carers

Some project staff observed that the generally poor level of provision for adult clients who are not elderly (that is, between the ages of 19 and 60) means that the needs of many carers caring for this group may well go un-noticed for years.

Few of the projects had worked much with young carers, though one project had just received funding to begin some work in that area.

Carers' interests and clients' interests

The reality of working with carers or clients is to come to grips with the actual and potential conflicts of carers' and clients' needs. On the one hand, they are inextricably linked; on the other, they need always to be considered separately. The two are often treated by statutory assessment as though they are identical. Recent legislation established the idea of carers having their needs considered separately, but the evidence is that this is rarely implemented.

All the projects in this programme were set up with the needs of carers, rather than those of the person cared for, in mind. In practice projects have had to consider the needs of both, in order to provide a quality service. For instance, in providing home care relief, the reliability and quality of the service is important to the carer. For the client, a good relationship with the care attendant, and interesting activities if appropriate, makes the experience pleasurable. A good quality service is in the interests of both: a carer who has had a break is more able to cope with caring, while a well-cared for client is a happier person to whom to return. Often the distinction between carer's and client's needs is not clear to the carer either. Parent carers of disabled children, when asked about their needs, repeatedly talked of what they needed for their children.

As well as large areas of overlapping interests, there are some areas in which the interests or wishes of carer and cared for may not coincide. One example of this is when the carer feels unable to continue caring for the client at home, and needs to consider residential care. This is an extremely difficult choice for many carers, even when it is quite plain that they cannot continue to care for their loved one at home. There are no right answers to this dilemma, but respite project staff and care attendants must be able to support and assist the carer as s/he finds her/his own response. The principles here are respect and restraint, helping the carer to explore her/his feelings and the practical options, without influencing the decision.

At the other end of the spectrum are carers who, from a sense of duty or because of family pressure, continue caring for someone long past the point of protecting their own interests. I spoke to one such carer, who caring for a friend because of a sense of christian commitment, told the long tale of how the client had been asked to leave all previous homes. The carer, with his life in his own home severely restricted by the client's needs and preferences, had long since lost any positive feeling towards the client. The dislike was mutual, and the client constantly criticised him. "Not a happy home," he commented. Holidays alone were impossible because the client insisted on going along; all that kept this carer going was the one day a month off by himself, afforded by the respite project.

Carers' demands are astonishingly modest

In 1994, Carers in Ealing conducted a survey among 150 carers with whom it had contact; it is a fairly safe assumption that these carers, in touch with at least one voluntary organisation, are at least as well supported as most carers. 84% of these carers provided over 50 hours of care a week, and just over half - 56% - provided over a hundred hours a week. 36% of these carers said that they received no help or support at all. A further 26% left this question blank, or scored it through, which suggests that a number of these people too receive little or no help. A much larger national survey conducted by Norman Warner on behalf of the Carers National Association,² revealed similarly low levels of service to carers.

Compared to the scale of what carers contribute, in economic as well as social terms, the figures are staggering. As far back as 1989, the Government acknowledged the care contribution made by family, friends and neighbours, and added that "a key responsibility of statutory service providers should be to do all they can to assist and support carers"³.

² Better Tomorrows, CNA 1995

³ In the White Paper 'Caring for people'

Consider the example of parent carers of a child with disabilities and challenging behaviour. Only a minority of families with the most severely disabled children receive any respite care at all. School holidays and weekends are demanding and stressful times, and the sisters and brothers of the disabled child need more of their parents' attention than they can often get (Which leads to further guilt and therefore further pressure on the parent carers. . .) Are these parents asking for weekly respite, or care over the long summer holidays? By and large their ambitions are much more modest. They are asking, typically, for 5-6 days respite care a year, plus 8-10 days playscheme access over the summer; this is rather less than what is available to many children without special needs in an average London borough. In a borough with a high priority on carers and with an active voluntary sector, they may even get some of what they want.

Carers' demands are modest indeed, compared to the scale of what they give. Indeed 'demand' seems too strong a word. Many carers ask once, politely, and when rebuffed, do not ask again; until a crisis occurs, which could perhaps have been averted by a little support earlier. Carers tend to ask for help later rather than sooner; or as one carer commented, "When a carer asks for help, they need help."

Accessible, Flexible & Caring: lessons about providing carers' services

This chapter explores further the lessons learnt through the programme in providing services which are accessible, flexible and caring.

These principles are most often found in organisations with a lively sense of the real impact of their practices on the people they serve, which in turn leads to high quality services. 'Putting people first' is not merely a vague slogan in such organisations, but a touchstone against which all activities are evaluated. Procedures are carefully thought through and assessed in terms of the value to carers, and the cost to staff. An organisation which treats its users well is also an organisation which treats its staff fairly, and supports them adequately.

Accessible: easy-to-reach services

Since the projects were concerned with improving carers' access to services, the question of how to reach carers in the first place was of paramount concern. Two fundamental strategies seem to have been adopted: first, more or less large scale advertising and promotion, and second, personal contacts, often through pre-existing groups connected with the target populations. These approaches are not mutually exclusive, nor in competition with each other; they merely represent either end of a wide spectrum of activity. Most projects used a combination of both methods. I have called the first, 'Publicity', and the second, 'Networking'.

Publicity

Most of the projects used printed publicity material (usually a simple leaflet). Leaflets alone were not enough to persuade carers to use a service. Instead they were usually used as a kind of calling card with carers, to remind them of a more personal conversation and give contact details. In publicising events, it was most effective to write (to libraries, clinics, social work teams etc) enclosing leaflets, and then follow up by phone.

The outreach stall

The outreach stall was most popular form of publicity activity, usually in a shopping centre or hospital. Several projects have found stalls effective, sometimes generating 40 or more new contacts in a single day. Choice of venue is important. For this kind of broad publicity exercise, the best site is visible from but just off a well-used pedestrian shopping thoroughfare; one project chose to set up outside a large chemist, where carers might pass on their way to collect prescriptions.

Other successful stall sites chosen by projects include the lobby of local hospitals for mentally ill people, outside supermarkets selling Asian foods, and religious centres. One worker commented that her stalls in Gurdwara and Mosque did not themselves attract much attention, but gave her a base and an identity from which to contact people more personally.

The key to successful outreach stalls seems to lie in the personal contact made between staff and carers. Workers on the stall do not merely give out leaflets, but chat to people who approach. This allows the carer to familiarise her/himself with what the project offers, and to make a personal contact; the leaflet acts a reminder of that contact. Many carers also allow the worker to add their names to a mailing list.

In projects with a role in representing carers and influencing public policy, the leaflet has some additional uses. The case study on the following page describes one project's effective use of its publicity material.

Using Publicity Material to Raise Public Profile

A project for carers' policy development, information and support, was being set up from scratch. It was important to develop a strong public profile: with professionals and politicians in order to gain an influential voice on policy; and with carers, to become a widely known and accepted resource, part of the carers' scheme of things.

30,000 leaflets were printed initially, in English and three Asian languages. The project had these ready for a large carers event organised by the local authority, and so was able to use the event as part of its launch. The Health Authority provided a set of address labels of professionals who might be interested; two or three leaflets were sent to everyone on the list, together with an order form for more. This broad-spectrum mailing was followed up by telephone contact, introducing the project and encouraging contacts to tell carers about it.

This process is periodically repeated, always with leaflet re-order forms. Take-up, monitored through the use of re-order forms, indicates that the approach justifies the time it takes. The value is not only in the potential contact with individual carers, but also the regular introduction of the project's name and role to professionals: leaflet distribution with a secondary marketing function.

The project also produces a newsletter, mailed regularly to its members, about 400 of whom are carers, and to a mailing list of two and a half thousand others who have an interest in, or contact with, carers. The content is designed to stimulate carers' awareness of their own needs and interests on a regular basis. An audio-tape version of the newsletter in Hindi has now been made available, but take-up so far has been poor. For many carers, the newsletter fosters a sense of support and belonging; at the very least, it keeps the project's name and role in mind.

Leaflets and other printed materials were generally found to be less useful for reaching carers who did not speak English. Having material translated does not solve the problem, as people may not read their mother tongue. Accurate targeting and distribution are also difficult; experience seems to suggest that leaflets are much less effective than a personal contact in getting the information across.

There are some other media worth considering for contacting non-English speakers. Community radio programmes in mother-tongue languages are very popular with Chinese speakers, and may also be a good way of reaching other isolated Asian language speakers. There is a Chinese news-sheet which reaches many isolated Chinese. Asian community organisations sometimes

provide mother-tongue newsletters which can print an article or a message. Cable TV too, may open up some new possibilities for voluntary organisations with something to offer non-English speakers.

Use of video

Both Asian and Chinese access workers mentioned video as a universally popular medium with their target communities. Indeed, the pitch outside the Asian Video shop was a successful outreach stall site in one borough. The same worker had used a video for carers in Hindi (from the Kings Fund Centre) to good effect with community groups.

Video also has great potential for reaching minority ethnic carers who are not in touch with community networks, by using ordinary distribution routes for videos in the relevant languages. As well as making videos for carers, ideas include seeking free or part-donated advertisements, either within the videos or to be distributed with them. Many Asian language videos are made in Britain, so negotiation with their producers is a possibility.

In the Chinese community, issues of distribution are simplified by the fact that most Chinese language videos are distributed to restaurant owners by one large chain, often alongside specialist food supplies. A free video or video advertisement could therefore reach many isolated Chinese carers more effectively than any other form of advertising.

Networking

The majority of the projects did not rely on leaflets or other material, but rather on outreach stalls and on contacts with carers made through networking. For funders, the most important lesson is that networking takes time. The first stage of the process involves developing contacts and relationships, and becoming known as well as getting to know. This takes at a minimum several months. There are no shortcuts, other than appointing someone who is already a part of the network the agency needs to enter. This has implications for the funding of development work in which networking is an important strategy.

One project coordinator commented that having sufficient funding for three years from the Carers' Programme allowed the project to protect its development time, rather than being swamped with one-to-one casework. The project had enough flexibility in its budget to be able to say 'yes' rather than 'no', and to experiment. This allowed creativity to be exercised, and was fruitful.

For providers, some lessons about effective networking emerged from the projects' collective experience:

- Where possible, work through existing groupings to save time. This could include day centres, community groups or more informal groupings. One enterprising access worker asked Asian shopkeepers about where they met with their friends.
- Locate partners who share or sympathise with your goals, and work with them.
- When contacting a new group, expect to make several visits. One-off visits are ineffective, because you need to become a consistent presence over time. Having said that, one white worker recruited four Asian carers after only three visits to an Asian day centre.
- Use the group to develop personal contact with individuals. Merely speaking at a meeting is effective in identifying you with the project, but is not enough by itself to make personal contacts.
- Be opportunistic, and join in with any events which come up, either to get your message across or simply to get your face known.
- Consider working jointly with willing colleagues from existing groupings which have a shared interest in getting your message across. An access project worked very effectively with a local Pan-Asian organisation to run information events for Asian parent carers. Not only did the event reach many more of the targeted carers, but the partner organisation was also educated about the issues and better able to represent carers' needs.
- When networking with professionals providing services to carers, try to have talked to carers first. Work from the carers' perceptions of the issues, rather than from a basis of professional scene-setting.

There may be some preparatory work to do in uncovering the groups you need, before you can make contact with them. Statutory, and organised voluntary groups are fairly easy to find. Some of the organisations the projects targeted for networking are shown below.

Local networking to contact carers can be carried out through:

- Community groups working with target communities
- Disability groups
- Religious centres and associated groups
- Cultural centres or groups
- Informal groupings (particularly important with smaller/more dispersed communities such as the Chinese community)
- Community Health Council
- Health professionals - GPs, Health Centres, District Nurses, Hospital Link Workers and Social Workers
- Social Services professionals - Social Workers, Home Help Co-ordinators, Day Centre Managers
- Education professionals -Psychologists, Special Needs Co-ordinators, Special School teachers and other staff
- Parents' groups and toy libraries
- Existing voluntary sector services for carers
- Shop-keepers.

The local Council for Voluntary Service will know many organised voluntary groups, and these groups will themselves know of other gatherings, more or less formally organised. Not every group you contacted may see itself as a group (yet). It may be a circle of women preparing food in the Gurdwara, the carers looking after the people who attend a day centre, or some men who meet to play Mahjonn. However, asking established contacts will uncover more people. Shopkeepers, distribution workers and others whose occupation or interests involve knowing what is going on, are also good people to ask.

Networking through religious centres

Using religious groupings to contact carers was generally found to be a very fruitful approach with Asian carers. All the Asian access workers had used religious networking, usually with good results. Because of the correspondence between religious and language groups, it is fairly easy to target particular language/cultural groups by means of their religious affiliations, though this does not of course enable 100% cover of that group. Most Bengali speakers are Muslim, but not all Bengalis can be contacted via the Mosque. Generalisations can also be a hindrance. Most Gujarati speakers are Hindu, but some are Muslim. Also, some carers are isolated even from their own community: divorced and widowed women, for instance, can sometimes fall outside the net.

Although workers had an advantage when working with the religious group of their own origins (whether or not they were devout), being from a different Asian religious group was not found to be a barrier to an access worker prepared to fit in. It simply meant that the work took longer, because relationships had to be built from scratch. There are some basic rules to this type of networking, shown below. All the access workers whose experience is distilled were Asian women.

Guidelines for religious networking:

- Turn up consistently over time so that your face becomes familiar
- Aim to win the support of the leaders, who will then direct people to you
- Wear traditional clothing, particularly at first
- Young access workers must be especially careful to be respectful of traditional values
- Don't act in a 'professional' or officious way; don't put yourself forward
- Behave as others behave, stay in the background
- Join in, take part in festivals
- Chat with people and develop personal contacts
- When you have been accepted, ask to set up a stall
- Be sensitive to culture conflict and generation differences between those Asians who first came to Britain as immigrants, and those who are British born and of Asian descent.

Networking in the Gurdwara

The carers' support worker wanted to set up a support group for Asian daughters-in-law, who were caring for the mother, father or another relative of their husband. Her experience was that these women were hard to contact, particularly in more traditional families, and that family pressure to care was so strong that even to acknowledge their own needs or feelings might be seen as a betrayal of duty. This meant that she had to proceed very cautiously, so as not to cause offence.

Coming from a Punjabi Sikh family, the worker was already well known at the Gurdwara, though she was not herself devout. She had already spent several months going weekly, and winning the confidence of the leaders there, and was becoming a well-known face. She noticed that on ladies' days, a number of women accompanied their frail mothers-in-law, who were coming to pray. The daughters-in-law usually left the older women upstairs, and went down to the kitchen to help prepare food. Food is very important in the Gurdwara (as it is in most Asian religious traditions), and to help prepare it is an act of devotion, so the daughters-in-law were behaving according to traditional values.

The support worker went into the kitchen too, and began to chat to the women in a very ordinary, companionable way, as they worked together. She built up friendships with some of the women who came every week, and gradually began to ask them about their caring responsibilities. This evolved into a very informal discussion group in the area outside the kitchen. After some months its members were able to share feelings and experiences, and offer each other support. The worker was also able to offer them information to which they would not otherwise have had access.

This worker saw the Gurdwara as a good place to contact Punjabi carers, because the Sikh religion, includes a tradition that food should always be provided free to anyone who needs it, so many elderly people spend a good deal of time there. They are transported by the relatives who care for them, who may therefore be approached.

The kind of approach outlined in the case study would also be appropriate for contacting Gujaratis or Hindus through the Temple, but contacting Bengali or Pakistani Muslims via the Mosque is somewhat different. Because the Mosque is largely the domain of men (though some Mosques have ladies' days), and all the access workers were women, they did less work in the Mosque itself. Instead they concentrated on Muslim groups and associations, and on social events held outside the Mosque. It is particularly important to target community leaders. Respect for elders is very strong, and young people must behave at all times with appropriate respect.

One worker sent her father, a well-known though non-Muslim local person, along to the Mosque to get information about what carers needed. He managed to make contacts with people willing to help, volunteers who then assisted carers in a variety of ways.

Socially and economically Bengali Muslims and Pakistani Muslims may be very different, though there is an emphasis on the unity of all Muslims. Among Bengalis, communities are often very close-knit, and the generation differences already touched upon may be particularly great. This is perhaps the group where an access worker who is her/himself Bengali Muslim has the greatest natural advantage.

A worker described a contact she had made with a local Buddhist group. She had asked first if she could look at their library, and subsequently had joined a meditation class, as a student, in her own time. She made a point of going to any festivals or events. Many of the Buddhists in this group were harijans, 'untouchables' in the caste system, who would not be contacted via other religious networks; she contacted three new carers through this work.

The Buddhist group also included some Tamils. The worker added that many more untouchables, and Tamils, were Christian, so that they could sometimes be contacted via churches. None of the access workers in the projects spoke Tamil, so there is little information to add about working with this group.

Religious networking is less useful in contacting Chinese carers, since public religion plays a smaller part in their culture. Some Chinese however, are Christian, and may perhaps be contacted via churches. The Buddhist group already described also had some links with Chinese Buddhists.

Most of the access work done in the projects was done with Asian or Chinese carers; it sheds little light on the issues in creating access for African-Caribbean carers.

A number of projects had tried to use Christian churches to contact carers of any ethnic origin, with patchy but, in the main, disappointing results. Black churches, however, are often more closely-knit, and might be a more useful source of referrals. Among non-Black churches, those with a commitment to social action may be the most fruitful for networking purposes.

Minority ethnic access to 'mainstream' services

The access projects all found that take up of mainstream services was very low among their target populations. A normal experience was that not only were most families on benefit receiving substantially less than their entitlement to state benefit, most were receiving little or no help from health or social services: no adaptations, social worker, respite, day care, home help, district nurse, occupational therapist, physiotherapist or therapy. This was often true even if an assessment had been carried out.

Access workers commented that most Asian carers are very unwilling to complain, and are grateful for even a poor level of service, which makes the problem worse. Access workers could achieve significant improvements for their carers and clients in almost all cases, where appropriate services existed. The largest gap by far was for appropriate respite services, either residential or domiciliary. Also significant in some areas was the absence of appropriate day care.

At the start of the projects' work in some areas, statutory service providers denied the need for 'special' provision for Asians, maintaining that mainstream services were already 'open to all'. Although some pockets of this attitude persist, by and large the access projects have at least established the principle, that service providers are responsible for making services accessible to users, not users responsible for accessing hard-to-reach services.

The lack of access to mainstream health and social services for Asians was tackled at three levels by the projects. Individual casework was an important part of all the access workers' roles, and has been effective in improving access for carers with whom the projects are in contact.

Working to influence the policy of statutory bodies in favour of minority ethnic carers has been an important area of work for several projects. Another level of work has also been needed, attempting to influence front-line service providers: social workers, district nurses, GPs, educational psychologists.

Levels of cross-cultural awareness were generally found to be low, and sometimes official procedures caused acute suffering among minority ethnic carers. One example of this is the process following a Muslim's death. Dealing with death is a duty of the whole community within Islam, not just that of the family or even the ethnic group. All practical matters relating to the death are dealt with by community members, allowing the close family to devote themselves

to mourning. Other Muslims of the same gender must bathe the body; others buy the cloth for the burial, read the Koran, and arrange for the burial. This means that the expectation of the 'next-of-kin' dealing with everything, is inappropriate and distressing to Muslims.

Faith requires that the body be bathed as soon as possible after death, and failure for this to be carried out in the proper way, is sacrilege. The delays attendant on waiting for a death certificate are highly distressing to devout Muslims, conflicting with their religion. In practice, hospitals do not release the remains soon enough.

Procedures could be changed or accelerated to accommodate this Muslim need. This cannot however happen until service providers understand why it is important, and have the will to create a more appropriate procedure in such cases.

The language barrier is one of the most important elements of this inaccessibility for Asian and Chinese carers. One access worker counts it as a modest success that after three years the statutory service providers with whom she works no longer use carers' or clients' children as interpreters, but seek recognised interpreters.

A dilemma for several access agencies, is what to do if statutory services ask them to interpret. Some do so, believing the advantages, to carers and to the relationship with service providers, outweigh the disadvantages. Some take a more robust line, and interpret only for a fee, to underline the fact that communication with all carers is the responsibility of the service provider.

In one project providing domiciliary care, a part-time worker had the role of encouraging access to respite services for Asian carers. This was harder and slower to achieve than access for white carers, because the Asian carers required more persuasion, in part because of cultural factors, and in part as a result of social isolation and low expectations. By the time the access worker did succeed in persuading some to apply, available hours were taken up, and the Asian carers had to wait. Where outreach work is targeted on specific hard-to-reach communities, it is helpful also to allocate a proportion of service hours to that community, so that carers do not have their hopes raised and then disappointed.

The need for transport was acute among Asian carers, since many were poor and did not own cars. In some cases projects tackled this through the use of volunteers. It raises however a wider issue, that of the accessibility and suitability of community transport schemes, which existed in some areas where this problem arose.

Flexible: meeting carers' real needs

The starting point in meeting carers' real needs is in finding out what they are. Some of the projects in the study began with a period of networking and contacting carers to establish what carers wanted, before designing their services. Some began by offering a particular service, but were prepared to modify it in the light of carers' responses, and/or to devote resources to 'selling' it to carers. Some, particularly those initially offering holiday respite, found that their package was not at the top of carers' list of priorities, and learned that they needed to be flexible in what they offered. This does not mean abandoning all structure, but offering options to carers within the limits of what is available.

Central to this flexibility are the individual needs of carers. Assessing what a carer needs must be a process of negotiation, and the agency must be prepared to modify the package as needs change. There must also be flexibility within the arrangement. In practice, it is a sign of success in most respite projects, when a carer who regularly has brief respite, is willing to entrust the cared-for person to them for a longer period.

Because carers are cautious in entrusting clients to another for care, the role of the care attendant and the continuity of her/his relationship with the carer is vital. All the home respite projects aim for the client always to be looked after by the same care attendant, with a second care attendant as consistent back-up. The case study on the following page describes a project which has been particularly consistent in maintaining this standard. It also illustrates an organisation alert to the impact of its own practices and boundaries, and prepared to modify these in the best interests of carers: in other words, an organisation able and willing to learn.

Organising for Flexible Care

The project provides home care to elderly mentally ill people, to allow their carers some regular time off. It is very popular and has a waiting list. Applicants are not assessed until they can be offered a service. The scheme is very flexible, offering daytime respite, up to two nights' respite per week, occasional longer breaks, and monitoring of clients who are in residential respite, enabling carers to make full use of breaks provided by other sources. In common with other carers, most make light use of the service at first, but heavier use as time goes on.

CPF funding enabled the scheme to offer a night as well as a day-time service. The night care scheme was originally set up with a separate coordinator, but because of the ethos and structure of the organisation, used the same pool of care attendants. The coordinator spent a good deal of his time supporting carers directly, and giving advice and information about practical matters such as benefits and services. As the CPF funding came to a close, the project re-integrated the administration of the night scheme with the day scheme, which was far more efficient. It used the resources thus freed to create an information and support post, which the previous worker's experience indicated was more useful to the carers.

Carers are visited by a coordinator first; the carer's perception of her/his needs is the starting point for assessment. S/he is then introduced to a care attendant, who visits once or twice before beginning work. A second care attendant is introduced as permanent back-up. All other care attendants in that staff meeting group (there are two groups meeting weekly) are briefed weekly, so that should the back-up fail, the next replacement will be well-informed about the family. During the initial stage the relationships between carer, client and care attendant are carefully monitored, and feedback is sought from each. If conflict arises, the project quickly involves itself in helping resolution.

Dealing with racism in home respite work

Occasionally the project, which employs many black and Irish care attendants, encounters racism on the part of carers or clients. It will not collude with racist carers, but has had to accept that clients' racist attitudes may not be changeable, since clients are usually dementia patients. The project does not expect black staff to work with racist clients. Where the problem is attributed to the client by the carer, but the project suspects that it may lie with the carer, it probes further, and consults the care attendant. It does not automatically replace the care attendant, but considers the particular case, and the interests and wishes of the member of staff.

An early review of the night scheme arrangements resulted in an extension of the night 'shift' by two hours. Carers were spending the first two hours of the respite, ostensibly briefing the care attendants, but actually unwinding after the demands of the day. After doing so, they were able to retire and get a good night's sleep.

Once the relationship is established, the care attendant is entrusted with the responsibility to monitor the family's needs and changing requirements. This is fed back into the organisation via a weekly staff meeting. Care attendants are encouraged to apply their own skills and interests to the relationship with the client, and matching is done with these in mind. For instance, a former hairdresser cares for a client who enjoys grooming, a psychology student for someone who needs stimulation, musicians for someone who like music. Care attendants may give medication (the project holds medicines for some clients in its offices). Duties are wide ranging, and care attendants are encouraged to seek support and guidance in areas where they feel less confident.

Because the client group of this service are often not physically ill, their use of the project tends to be long term. The project does not offer a time-limited service, but regards the taking on of a carer and client as a commitment. Relationships with care attendants normally continue for some years, and become very important. Because of this endings are as significant as beginnings, and the care attendant will visit the carer two or three times after the client's death or admission to permanent residential care.

Excellent care attendants

The project has been very successful in retaining skilled and committed care attendants, who typically stay for several years, and develop considerable skill over the period. In a field of employment where turnover is often rapid, staff demoralised, and quality of work poor, this is a substantial achievement and deserves closer examination. It is based on careful recruitment, strong support, recognition and development of care attendant skills, and good conditions of employment.

Recruitment and induction

Recruitment is a structured, formal process, unlike many in this field of employment. An advertisement is placed in several local papers, and usually generates around 200 responses. Each person is sent an information pack, which is designed to put off unsuitable applicants. As well as information about the work and an application form, it contains a person specification and job description. Applicants are shortlisted and interviewed formally.

The project has a very clear idea what it is looking for, but is not concerned with formal qualifications or even experience. Instead it seeks personal qualities. The important factors are that the applicant should be genuinely interested in care work; that s/he should be emotionally stable and empathetic; very flexible in her/his attitudes; and open to learning. It is important that applicants can become very involved with a family, while retaining the capacity to step back. The rest is negotiable.

The care attendants themselves confirmed the need for these qualities. They spoke of the pain of watching someone with dementia deteriorating, and of the 'living bereavement' of the carer. They added "You need a broad back. There are good days and bad days, but you only remember the good".

When asked what motivated them, care attendants spoke of the challenge of making the client's day as comfortable and happy as possible, and the joy and excitement of creating an experience the client enjoyed, or the client doing something new for her/himself. They mentioned variety: "Every day is different, it's not dull"; "Touching home to reality"; and of the hope that if they were in the same situation, someone would do the same for them.

After being accepted, care attendants have a six-month induction and probationary period. They have two days' formal training, covering basics such as lifting and carrying, confidentiality, and what to do if problems arise. There is then a three-week period of informal training, through weekly meetings and shadowing. A new care attendant typically shadows seven to nine experienced care attendants, some of whom care for clients whom the new worker may take on. They also spend time in the office, and visit day centres (to join in, not observe). During this period the care attendant is not responsible for a client. Towards the end of the period s/he will be matched to a client, and begin work.

Support and development

In this project there is a convincing recognition of the demanding work that care attendants do, and a strong emphasis on support. Care attendants attend a half-day weekly staff meeting as part of their working week. As well as practical matters such as rotas and holidays, there is a de-briefing session on their work, and an opportunity to raise any concerns or problems. It is a well-used source of support as clients, whom the care attendants have usually known over years, deteriorate or die. There is a strong sense of trust and mutual support in the group.

The project formerly gave each care attendant one-to-one supervision (which may still be initiated if needed either by managers or by care attendants) but finds that the supportive environment of the group, all doing the same demanding work, is more effective. In another respite project, group supervision of care attendants was chosen primarily for economic reasons, but also found to be highly constructive. The staff meeting allows for informal training, and discussion of policy and issues of common concern.

There is a recognition within the project of the complex and demanding work care attendants do. They manage a relationship with carer and client, with all the nuances that involves, over a period typically of around five years. If their work with carers were done in another context, it would be called counselling. Care attendants themselves speak of it simply as helping carers in 'coming to terms', and emphasised how important it was to discard assumptions, so that the support allows the carer to make difficult decisions for her/himself. Similarly, they apply great skill and ingenuity to their relationships with clients, the majority of whom are dementia patients. This is encouraged and supported by the project.

Pay and conditions

Care attendants' hourly rates are slightly above local social services norms. They are guaranteed a minimum weekly wage equivalent to 35 hours paid at the basic rate, which applies only during the day and during the week. In practice they continuously work unsocial hours, so a typical week might be two 12 hour night shifts at time-and-a-third, $(2 \times 12 \times 4) \div 3 = 32$ 'basic' hours, plus a three hour staff meeting, totalling 35 hours. In addition to the night rate mentioned, care attendants are paid time-and-a-half for work on Saturdays or sessional work (not whole nights) between 6pm and 9am, and double-time for Sundays. They are paid for travelling time, and receive holiday and sickness pay.

Some may feel that these conditions are too good to be widely replicated. The organisation's director is clear they are necessary. At these rates, he can offer case-by-case contracting to the local social services department at £10.25 per hour (1996-97 rates), for a high quality service provided by an experienced care attendant. Local commercial agencies offer a rate about £1.00 per hour less than this, but often so poor a service that the money is completely wasted. Not infrequently agency care attendants are refused admission on their second visit, because client or carer regard the quality of the care as unacceptable. Is it better to spend £1,000 on a car that works, or £900 on one that does not?

The fact that the pool of care attendants do all respite work (night, day and longer periods) mean that there are enough of them to make this arrangement possible: an argument for integrated respite schemes. There are 'economies of scale' here, though in fact a strength of the project is "the luxury of being small" (compared to the statutory sector, at least). The organisation is small enough that everyone is known and feels that they have a place and a role. Below a minimum number of care hours a week, such an arrangement would become uneconomic. The 'one carer-one care attendant' arrangement, and the relative elasticity of resources as a result of case-by-case contracting, makes the minimum smaller than might be imagined.

Another project experienced initial difficulty in recruiting care attendants. It had tried formal advertisements in the local papers, and various kinds of local networking, without success. It decided to take a slightly different approach to recruitment. It made its procedures much less formal, advertising in an inviting way and setting up an open day to give prospective applicants information. There were 150 responses to its advertisement, and 70 people attended the open day. From this process 10-12 good quality care attendants were recruited, most of whom are still with the project two years later. They included several students with relevant interests: music therapists, psychology and medical students.

What the approach did have in common with the one in the case study, was the fact that the criteria were pared down to the minimum essential: experience criteria were dropped. The project required only that applicants should be caring, responsible, reliable people. In this project too, there is a strong emphasis on support and supervision for care attendants, and on allowing care attendants to develop their role.

A strong group of care attendants requires:

- Effective recruitment and induction
- Regular, meaningful support
- Recognition and development of skills
- Consistency and good conditions of employment.

The delegation of considerable responsibility to care attendants echoes an experiment carried out in the North East of England in the late 1980s. Individual social workers, with a maximum caseload of 25-30 families, were given control of the families' care budgets, up to a limit of two-thirds of the cost of maintaining the cared for in a residential setting. The experiment was a success, allowing social workers to develop very individualised responses to problems. 'The carers who received the case management service had significantly greater reductions in their levels of difficulty in coping with day to day activities.. than those receiving the usual range of services. There were similar reductions in the degree of psychological stress and burden felt'⁴

Caring: Carers' relationship with project workers

The relationship between project workers and carers was critical to success in all the projects. In order to persuade carers to use the new services, it was vital for carers to feel that they could trust and rely on the workers. A common factor among the projects was that staff were caring and approachable people.

Many of the project staff were not only caring, they were impressive in other ways: impassioned, obliging ("no problem"), imaginative, adaptable ("fleet-of-foot" as a funding officer commented), and engaging. The value of interpersonal skills in developmental work is hard to over-estimate. Staff responded to carers as people, and this underpinned their success.

This caring environment was ideal for the carers; for the staff themselves, over time it could generate a level of pressure which needed to be managed. The case study mentioned above shows how these pressures were managed among a group of care attendants. Project staff too have the strain of demanding work, and need good quality support.

This general state of affairs was doubly true for the Asian access workers. Unsurprisingly, the most successful projects at making and maintaining contact with minority ethnic carers, were those employing staff from those communities; this was true even when the worker's post was not specifically targeted on minority ethnic carers.

⁴ Reported in PSSRU Bulletin No 7, April 1990 p12 Challis D & Traske, K.

To be successful, the relationship had to be “more personal, less professional”: because the cultural norm is for care to be provided to elders by younger family members, the access workers became, in the eyes of their carers, honorary ‘daughters’. Recruitment was sometimes done with an eye to the candidates’ aptness for this role. The access workers were often Asian women of a younger generation, born in Britain.

While this way of working was culturally appropriate and has been highly effective, it was not without cost for the access workers themselves. There was the pressure of providing emotional support to carers who frequently had no one else to whom they could talk freely. All the access workers carried large and increasing case loads; these posts were stressful from the sheer volume of demand. There were also the problems of success: the more successful an access worker was, the more pressure she experienced.

As advocates for the carers within the system of statutory services, the workers took on an additional role, that of sponsor, ‘making things happen’. There was (and is) a strong expectation that any problem raised be dealt with personally. In many cases, the continuing difficulty of accessibility to statutory services meant that it was necessary to take matters up personally, to ensure that the outcome was what was needed.

Staff dealt with the pressures in various ways. Some worked extremely hard to meet the expectation; some of these seeing the demand as time-limited and therefore manageable. Most access workers spoke of the frequent experience of being told by carers “You are my daughter”. Only one said “I’m not their daughter!” This worker had a very clear sense of which demands she could meet and which she could not. She referred extensively to other people in her network, usually other Asian community workers or activists she knew would help.

Perhaps significantly, that worker’s primary responsibility was not for access work, though she had been very effective in that area. The responsibility for access may in itself generate extremely high expectations of a worker, not least in the worker’s own mind. Their very considerable achievements are no doubt due in large part to the workers’ high expectations of themselves. It is a tribute to these workers that they achieved so much in so short a time.