

There is rarely more than one access worker in a project, and where there were two, mutual support seems to have been important. Access workers can easily feel isolated, and (like care attendants) need effective support, either within the organisation, or beyond. More than one worker mentioned how valuable they had found support groups, or mentioned a particularly supportive manager or management committee chair.

Effective relationships between local projects and larger groupings

A problem that emerged in the early stages of some projects was a difficulty in recruiting, because the posts required too many skills, often poorly prioritised. While time brought greater precision to most, it was refreshing to hear one manager (who had recruited successfully at the outset) attribute much of the success of the development worker to her warmth of character. When asked about the worker's report writing, she blinked and said "You can't have everything". Parent organisations' ability to prioritise essential characteristics, was a crucial efficiency factor.

Several project staff testified to the importance of groupings where they could freely discuss their work and get support from colleagues engaged in similar work or with similar concerns. As well as the CPF meeting, Carers National Association groups were mentioned, as were local groupings of Asian women or Asian access workers.

Several of the projects were local schemes affiliated to national organisations. All these schemes had some support and help from the umbrella bodies, but one stood out as making extremely positive use of this relationship. It is described in the case study on the following page.

A Productive Link with a National Organisation

The national organisation was experienced at setting up and supporting regional and local development work. "The process starts by recruiting people with initiative and development experience," the manager commented. "Then we devote time at the start to developing a contract between the local development worker and an individual manager at the national office. We also introduce new staff to everyone here, because national staff are a resource they can use, for instance for information backup." Further examples of tangible help were the packages of materials which could be used in setting up one day events and workshops. The local worker observed that she had been given a very thorough induction, with time at the national and other regional centres.

The organisation had a strong emphasis on regular supervision, and on training, which it ran internally and purchased from outside. More than that, the national manager gave priority to being available to local staff, for instance in returning their calls quickly. "We probably speak two to three times a week. If I can't speak immediately, I call back the same day. I keep telling them I'm available, so I have to show that I mean it."

"It can be a very lonely job," commented the local worker, "But my manager is very faithful and supportive; he is always at the end of the phone. We are kept very well-informed. There is a stress on communication in this organisation." She added that quarterly meetings of all local and regional development workers had been invaluable to her, giving them all the chance to bounce ideas around and to learn from each other. "It has saved me many a mistake."

The regional development meetings were two-day events with speakers, discussion of issues, informal training and discussion of organisational policy. Mutual support was part of their purpose, and the middle evening was always celebrated with a collective meal out. The regular meetings also stimulated informal contact and sharing among regional offices between meetings, since everyone knew what everyone else was working on and whom to approach for advice.

Contrasting models of development work

Among the eleven projects there was a wide diversity of approach to the development role. These different approaches each had their strengths and limitations.

In some of the access projects, the model involved seeking out and giving intensive support to a limited number of individuals. The focus was narrow, in the sense that the group of people directly affected was relatively small (though projects also applied what they learned from their casework to their efforts to influence local policy). The 'task' in these projects was much broader in focus, for workers would try to respond to individuals' needs, whatever they were. The model seems to have been very successful in improving access to services by these individuals, and has much to recommend it as a short-to-medium term method where ethnic minority services are not able to access 'mainstream' services. There must however be a context of appropriate services for carers, particularly respite services, if it is truly to lead to access.

In some other projects, the need to tackle carers' rights and interests across a broader spectrum led to offering a more circumscribed service to a broader range of carers. Sometimes this was combined with the more intensive 'access' approach within the same project. This combination can lead to problems if undertaken without the fullest discussion. Staff's very different roles can lead to very different analyses, and to conflicts over priorities because 'important' tasks are perceived differently. A project operating these two different models needs to consider how their linking can be established and maintained.

One project adopted a focused, strategic and time-limited approach. The focus was the need of the group of carers, in this case, parent carers. The criterion that work undertaken must have a strategic value, that is, be of lasting benefit to a wide group of these carers, helped staff to prioritise work. A positive merit was made of the fact that the project was time-limited, forcing staff, and their partners in other agencies, always to consider what would happen when the project ended.

None of these models constitutes the 'right' way to do development work with carers. They all offered different kinds of benefit to carers.

More about Services: Holistic Information, Support and Respite

This chapter expands some of the information given earlier about the services provided by the projects, describes some of the policy work, and considers some aspects of the relationship between projects and their parent organisations.

Holistic services

Most of the projects aim to provide their carers' services in a holistic way, that is, in a way which takes account of the whole person with all her/his needs. Where the project cannot provide all the services that the carer needs, it tries to arrange for that service to be provided elsewhere. Some go further and aim to provide as many as possible of the services carers need. From the carers' point of view, it makes obvious sense to have to contact only one organisation rather than several, but the reality of scarce resources makes a carers' 'one-stop shop' still a remote prospect.

The skills demonstrated in the respite projects were in practice rather different from those of the information and policy projects, and none could meet every information, support and respite need. An effective network of provision, including statutory provision, in each area, and with good quality information for the left hand about the activities of the right, seems a more realistic target.

Since many activities engaged in by the projects serve more than one purpose, in practice it can be difficult to separate information work with professionals from policy work, and pointless to ignore the supportive function of giving good quality information to carers. Respite is somewhat different, but respite projects within the scheme were also involved in providing information and advice to carers, or working closely with others who did.

The question of integrating services for minority ethnic communities also raises the question of whether it is not better to apply pressure on statutory providers to make 'mainstream' services accessible. Carers' own preferences are important here, as is urgent action: minority ethnic carers in general receive a far poorer range of services. Given the absence of appropriate respite care for Asian clients, domiciliary respite deserves serious consideration. It can be set up quickly, which is important given the scale and the urgency of the need.

Information

The information projects all engaged in one-to-one casework, and in most cases also attempted to influence public policy locally in favour of carers. Access workers tended to visit carers at home, and provided a much more intensive level of support. Other projects limited themselves to telephone advice, either ad-hoc, or within a

Work with Parent Carers on the Transition from Childhood to Adult Services, and the Needs of Brothers and Sisters of the Child with Special Needs

The time of transition to adult services is an anxious one for parent carers, partly because of the limited services available to young adults with disabilities, and partly because of the emotional impact and implications of the disabled young person reaching adulthood.

In response to this, staff organised an information event on a Saturday, with lunch and full creche facilities. The structure of the day allowed for parents to get information from educational psychologists and other professionals about the needs of their 'other' children. There was also time to spend discussing the issues in small groups, which many parents said made them feel better: "More able to get out there and fight for what we need. It was also good to realise that others have the same fears about the future."

As it had done before at similar events, the project invited many professionals and mixed them up with the parents. The professionals too found the new insights into parents' dilemmas very enlightening, and very moving.

There was a good deal of written information to be gathered on the main topic and other topics of interest to parents. Afterwards a parent commented "It was brilliant -- so well organised. They think of everything, down to the carrier bags for you to take away the papers in!"

Parents' caring for the child with special needs, with all the time and attention it requires, also has a big impact on the family's other children. 'Other' children too experience ambivalent feelings towards their disabled sibling: resentment, guilt and protectiveness. Future health depended on expressing and working through these feelings, so it was critical that parents understand this need.

The project chose to work with this concern in a much more informal and intimate way, by organising workshops where parents could share their concerns with each other and with a few professionals. Comments included: "Less guilty and less alone." "It's such a relief to know that other people have the same problems."

An outreach worker wanted to reach carers on an isolated estate with few facilities. Using her local knowledge, she targeted the pharmacist and manager of the local chemist, and contacted the community association, GPs and district nurses to reach carers with news of a one day event. The event was designed to get basic information to carers, introduce carers to relevant professionals, and launch a new support group. 47 carers attended.

Another project set up a conference where the spoken language was Hindi, with all women speakers. Professionals, such as psychiatrists, community psychiatric nurses and the befriending co-ordinator, gave information about available services, lifting and handling etc., and there were small group discussions for mutual support. The day was a great success.

In Asian communities mental health problems carry a severe stigma. The Health Agency decided to target not only carers, but also Asian community leaders, with better information about mental illness. The aim was to reduce the stigma and isolation of mentally ill people and their carers. The local access project worked in close partnership, encouraging people to attend, and helping to plan the event.

The stigma of mental illness is also exacerbated among Chinese people, as indeed, to a lesser extent, is illness generally. In giving Chinese people information about these topics, it is important not to mention illness, but to take a more indirect and positive route, focusing on health and how to maintain it. In this context, information about the causes and the curability of mental illness can be given in an acceptable form.

Policy development work

A number of information-based projects had a role in promoting the interests of carers on the local policy agenda; many of the projects were able to point to some solid advances in local authority behaviour as a result of their intervention.

Time -Limited Development Work

One of the projects was set up as a time-limited piece of work, to generate some improvements for parent carers in three boroughs during its three-year tenure. After an initial period putting the project on the map, there were many requests received for input from the project. Each request was carefully considered in the light of its likely strategic impact, and the availability of other resources to address that need. "The role is to bring people together to think things through, not to do things". Nevertheless, carer perception of the project was that staff "got things done".

The project resisted running any ongoing services, such as summer playschemes (a strongly identified need). Instead staff would work with partners in other statutory and voluntary agencies to establish playschemes which would continue to run after the project's close, or to promote the integration of children with special needs into existing playschemes. Staff had been invited to join senior policy groups in all three boroughs, giving many chances to raise ideas and issues. Ad hoc working parties on specific issues were another favoured form of influence. The value of the approach was affirmed by parent carers, who noticed a significant shift in professionals' attitudes towards them. They attributed this particularly to the information events bringing together professionals and parents.

Published information was also used to good effect. The project produced and published a borough guide to carers' services which was so popular that the first print (2000 copies) was taken within a month. The guide is on disk so it can easily be updated, and the local authority committed itself to do so.

The work programme was designed around themes or topics of value to parent carers, such as leisure. There was an emphasis on organising one-off events with a lasting value in themselves, such as days on challenging behaviour and on the young adult options. Some of them were targeted on Asian communities, working closely with partners in an Asian community association. All had creche facilities, except for events designed for the whole family to attend, such as summer art or music days.

In the last year of working, staff began to focus their attention on how to hand over the work to volunteers and partner professionals who would continue to press the interests of parent carers. There was however a strong sense of impending loss among carers, and the realisation among staff that the three years have been too short to consolidate the achievements. Hence a further three year funding was secured, though at a reduced level.

The project in this case study successfully embodied the role of 'expert consultant' to the local authorities providing services to carers. Another role adopted by projects engaging in policy work has been that of 'lobbyist'. Working from the base of being the recognised forum for carers in a borough, one worker estimated that she spent 40% of her time putting pressure on the local social service department, and that she split this work with carer members of her management committee. Relationships with the Director and Deputy Directors are good, but their enlightened attitudes are not always reflected throughout the department, and liaison at all levels is essential.

This worker is also involved in training staff who deal with carers. Carers are prominent on the political agenda in this borough, and can point to some impressive achievements: the establishment of several new respite schemes, including some in the voluntary sector, and the funding of a Young Carers' post through joint finance. Resources were invested to make Carers' Week an event in the borough, and carers are now being consulted on the community care plan.

Asked for her advice to others facing similar tasks, the worker counselled patience and persistence alongside a commitment to consulting carers, even when the process of consultation is unwieldy. Observation suggests that her passion for the cause of carers, together with that of the carers she worked with, was also a critical factor.

A worker with a similar role in a neighbouring borough advised being 'cheeky': "If you don't ask, you don't get!" She also felt that it was important to stick to the basics, and keep repeating them till the message got through. Her agency was particularly skilled at adopting a multi-layered approach, ensuring that the message got through several times a year via as many different media as possible.

Working on policy committees is an obvious strategy for those wishing to influence policy. In one project, a complex structure had been designed and implemented to ensure that carers' voices were heard in the process of community care planning. It involved six groups of carers, representing particular interests, meeting with a smaller number of professionals, who were then responsible for feeding those views back into the planning structure.

Carers' assessments

Some projects had worked on encouraging carers to request assessments of their own needs separately from those of the cared-for person. In some boroughs assessments were still carried out jointly, and in many social services staff were still very unclear about carers' assessments. Assessments were generally agreed to be valuable in highlighting (not least to carers themselves) the legitimacy of their claims, but in practice were hard to obtain. Many staff were ambivalent about them, since without additional resources they did not necessarily make a difference to the services actually received by a carer, and in some cases might raise expectations which would then be disappointed. Notwithstanding these concerns projects felt that the principle of carer assessment was an important one, and that all care managers should be trained on the legislation and about carers' needs. A number of projects were involved in carrying out such training with social services staff.

Building a relationship with professionals

Several projects began their work with an intensive period meeting potential partners, among the statutory sector and in the community. In some cases, there was a good response to this, in the sense that referrals began to flow immediately. Sometimes, even going to speak to groups of providers had no effect; a different approach was needed. Collaboration was more effective, allowing a gradual process of education of practitioners. This sometimes involved ad-hoc temporary groups working on some particular issue or area of provision.

Joint case-working was another approach commonly used. Access workers helped social workers to do assessments, or supported and worked closely with hospital link workers. The greater access to services achieved through the access workers' efforts also has a knock-on effect: service staff are becoming somewhat more accustomed to Asian carers and clients, and have a better understanding of their needs and customs. It would be wrong to suggest that statutory services have been transformed, but access workers can point to small but definite improvements in the services offered to Asian carers.

Some projects worked jointly with professionals on ad-hoc working parties, or on information events, which had the effect of broadening the professionals', as well as the carers', information and experience.

Working with GPs

GPs are an obvious group of professionals in touch with carers, mentioned in the Four Boroughs Report as being particularly poor at referring carers to appropriate services. Several of the projects devoted considerable energy to trying to contact GPs to generate referrals. In most cases the results were disappointing. It was difficult even to get to speak to the doctors themselves, and contacts with practice managers or other administrative staff proved fruitless.

Some lessons were learned, however. It was essential to contact the doctors, or other medical staff. Sometimes district nurses or other medical staff attached to a GP practice or Health Centre proved to be a good route to contacting the doctors. Going to health centre staff meetings and speaking to medical staff directly was felt to be the best use of such an opportunity. It did not however always lead to the level of referrals the projects wanted.

While writing to doctors was unproductive, one respite project came up with an ingenious marketing device which over time had had an impact on its relationship with GPs. Each time they took on a new carer and client, they wrote to the client's doctor saying that they were doing so, giving some general information about the project, and enclosing a leaflet. Because the letter was about a patient, it had to be given to the GP her/himself, and over time GPs became more aware of the service and began to request more copies of the leaflet.

As with other kinds of networking, one of the most important routes to success is to find and work with individuals who share, or at least sympathise with, your aims. The same project had a good relationship with the local hospital's consultant psychiatrist, who would refer directly. They also had close links with two GPs at a local Health Centre; these doctors in turn spread the word among other GPs.

Another project has devised an inventive means of identifying older hidden carers from GPs records, with the cooperation of a local practice. GPs are required to do routine health checks for the over-75s. The project employed a researcher to go through the practice's records of these checks to identify carers and cared-for persons.

This identified 135 people; a process of checking further and narrowing the list produced about 58 carers to whom the project might be relevant. The work of identifying them had taken about 45 hours. This pilot work raises exciting possibilities for identifying hidden carers, provided GP's cooperation can be won.

The same project regularly mails GP practices, attends team meetings, uses and helps Family Health Services Authority and Health Agency contacts whenever possible. "We use every opportunity, and always respond, whatever they want: displays, leaflets," the coordinator said. "It's water dripping on stone."

Another project runs a carers' support group which is based on a GP practice, though it meets in the members' homes. The practice is forward-thinking, with transport, and volunteers who do shopping, for patients. It also has a Patients' Association. The chair, a carer herself, contacted the outreach worker. Together they spoke to the GPs at their team meeting; the doctors then began to refer carers to the group. The group is vigorous and lively, needing little support from the outreach worker. Once again, one interested individual was the means by which a useful piece of work was achieved.

Setting up a Carers' Support Group

The outreach worker agreed with the manager of a local day centre to invite carers of the patients to join a support group. She spoke to all the carers she could, and wrote to the rest. About eight attended an initial meeting held at the centre, and agreed to meet once a month. The worker agreed to arrange speakers for alternate meetings, and to facilitate a group discussion for the others. After a year the group had a regular attendance of 12 to 20 people. All sorts of issues were discussed, and group members raised issues for which they wanted a speaker to be booked. The group discussions were unstructured and wide-ranging, but most members found them supportive.

The group began to arrange social outings once or twice a year. Aware that the funding for her post was coming to an end, the outreach worker gradually began to hand over responsibility for the group to group members. After leaving the group, she kept in touch with the coordinators by phone, and let them know that they could phone her when they needed to.

A number of projects set up support groups for carers. Any group is unique, and will have its own style and preferred activities. Some groups are wholly support or discussion based, some aim to provide information useful to members, and some are purely social.

An access worker with very isolated elderly Asian carers felt that a support group was the wrong approach for her clients at first. Instead she concentrated on providing and organising less threatening one-to-one support. In a different part of London, another worker, over time, was able to start an Asian women carers' group. Like the one in the case study, the group combined information input with unstructured discussion time, and the combination was found very supportive by members. Speakers' subjects included diet, exercise, incontinence, benefit rights, osteopathy, the menopause, and HIV/AIDS. It was important to provide transport or funds to pay for transport for group members. Transport is a major problem for many Asian carers, and must always be considered in providing services for them.

An Asian women's group in another project, composed of carers of Alzheimers patients, was almost wholly geared to support through unstructured discussion. A mixed women's group, with carers for people with many different conditions, engaged in a wide range of activities: yoga, massage, relaxation, outings. The management committee wanted the worker to leave the group to become self-supporting, but she argued that this would fundamentally undermine the group: "carers want not to be responsible for a while, not to make an effort. That is what makes the group different from the rest of their lives."

For some Asian carers, particularly Muslims, it is important to provide women-only groups. In other cases, mixed groups are fine. As well as the question of gender, language is an important consideration. Members of the group must be able to communicate with each other, though this does not mean always segregating people along strict language/geographical lines, since many Asian people speak two or more languages.

Setting Up a Carers' Support Network

The management committee had decided that project staff should set up a network for isolated carers to provide each other with one-to-one support. The project wrote to 200 carers, setting out what was proposed, and asking for views. There were 40 responses from interested carers and ex-carers. A number of ex-carers, recently bereaved, or whose cared-for person had gone into residential care, were very keen to help. Interested carers were asked to write briefly about themselves, to help in matching the pairs. As part of this process, some of the ex-carer volunteers assumed responsibility for a particular geographical area, and visited carers.

The project organised a training day for interested carers, but felt in retrospect that an informal social event would have been more appropriate. Regular social events (for which staff fundraise) now underpin the one-to-one phone relationships which are the main point of the network.

At the same time on Christmas Eve, 20 carers and ex-carers were on the phone to each other: the network had begun. This relatively formal inauguration added to carers' sense of being part of something larger.

Six months later, the network supports about 30 carers, with regular word-of-mouth referrals. One pair, who live in adjacent roads, soon met in person, and have become fast friends. The role of ex-carers has been very important, with some taking on support of two or three carers; the network has provided them with an opportunity to help which contributed to their self-esteem.

Respite

The need for time off is fundamental for carers. Carers who are socially isolated may need not only to have time off, but also to have social events organised which allow them to enjoy the time away. Social isolation may arise from a number of causes. The carer may have spent so long in the caring role that other relationships have dropped away. This can be particularly true for those caring for someone whose behaviour is challenging or embarrassing, such as some people with dementia. Working with socially isolated carers, projects have organised outings or social events for groups of carers, sometimes based round an existing service such as a day centre.

Carers from some minority ethnic communities, such as Chinese and Asian people, may find that the stigma of disability or mental illness reduces their social options within the community. Such carers may be doubly isolated because they have no resources outside the community. An Asian access worker said that the usual response when she raised the issue of respite care to allow the carer free time, was “Where do you want me to go? I know no one here.” A broad definition of respite, and a flexibility of response, is important in providing services for Asian carers.

Issues in providing breaks to Asian carers

Asian access workers have adopted a flexible approach to ‘respite’, for example, setting up arrangements where the care attendant visits and chats with the client, allowing the carer free time in the home; or arranging for two care attendants, one to sit with the client and one to take the carer to the shops or to the Mosque; or arranging for someone to accompany client and carer to hospital or to the Gurdwara.

Care attendants in almost all the projects were paid staff. In only one case, an Asian access project, was the attempt made to recruit volunteers to act as care attendants; the reasons for this were primarily financial. The need for respite had been identified, but there were no resources to meet it in the project, and little more in the borough as a whole. The project, despite considerable efforts, never succeeded in attracting more than a handful of volunteers. The lack of volunteers seems to have been the result partly of economic and partly of cultural factors.

The project was based in an area where most Asians are not wealthy, but working hard to survive, and so with little time for volunteering. More fundamentally, the concept of “volunteering” is unfamiliar to most Asian cultures, where social obligations are dealt with via concepts of duty, particularly the duty of younger generations towards elders within the family. In the cases where volunteering has worked, the volunteer has become ‘one of the family’ (this is also the attitude most Asian carers have to the access workers themselves).

The impact of immigration to Britain has however made social patterns more complex. Adult children, many of them born in Britain and less influenced by traditional values, move away to work, and are not available to care for their parents. The extended family support system is breaking down, leaving many older Asian clients and carers high and dry, with no family support, and no state support either.

The perception by non-Asians that “Asians look after their own” is less and less true, but is particularly damaging to Asian elders, who are left with even less support than their white counterparts. All the Asian access workers found that information and support needs were very high, and that suitable respite opportunities either did not exist, or were extremely rare. This has implications for the organisation of access services.

Where these carers do not speak English, and/or are not wealthy, (and most of them are not), their situation may be bleak indeed. Some of the most disturbing circumstances in the project involved elderly Asian carers and clients. In my view, there is a most urgent need for suitable respite provision, both home-based and residential, for this group of carers and clients, in all the areas where access work makes it possible to guess at the scale of the need. In areas with significant Asian populations where no access, information or support work has been done, it can only be suspected that the level of hidden need is even higher. This is not work that can wait: time is running out for these carers.

In developing home-based or residential respite care for Asian carers, a process of consultation is essential to ensure suitable services. Religious and cultural requirements in such areas as food preparation, touching, dressing, washing, language and confidentiality must be addressed, both to produce appropriate services, and to reassure potential users that these concerns are taken seriously.

Good practice in setting up breaks for carers

Respite care in the home is a very intimate service, and some carers do not want to have it until they can see no alternative. This is even more true of night-time care. Where it works well, domiciliary care can offer an excellent solution, particularly with clients for whom residential care is disturbing, unsuitable or inadequate. Home respite projects work hard to ensure that the process is as relaxed as possible for carer and client.

It is important that access to respite should be direct and as trouble-free as possible for carers. One coordinator takes no more detail than name, address and phone number on referral. The next step is a visit, and an informal chat when information about the service can be given, and information about the carer and client, gained. Some further features of projects' good practice include: the care attendant meets the carer and client before starting work; full information is taken about the client's needs and preferences, as well as about the home, and the same care attendant(s) work with the same families. Most carers are concerned that the experience should be a positive one for the client too; projects' care attendants develop a relationship over time with both carer and client, often devoting considerable energy and skill to devising suitable activities with the client.

Day care services which take the client away for a few hours in the day, may well be valuable for clients, but even where available, do not meet the need of carers for respite. In many cases there are difficulties about transport or reliability which eat into the time, and the carer is always 'on call' if problems arise.

In the Carers' programme respite schemes, the carer is not 'on call' unless s/he wishes to be. Some carers prefer to be 'on call' during longer breaks, but all know that if they do not, the project staff will take full responsibility for backing up the care attendant if needed. Some projects also offer a back-up service when the client goes into temporary residential care, so that the carer can go away for a few days without being 'on call'. Because of the trust built up over time, many carers are happy to allow project staff to oversee a residential stay.

Do carers want holidays?

Two projects were set up to offer one-week home-based holiday respite care, which on the face of it sounds like a splendid opportunity for carers. They found few takers at first. Perhaps the gap between what carers presently had and what was offered was too great. Certainly there were initial fears about whether the cared-for person would be adequately looked after. Carers habituated to their role day-in, day-out, could not so easily drop it for a whole week. Both projects found it necessary to build up the trust of carers by offering much briefer, more regular respite at first, which enabled some carers to take the larger step of entrusting their loved one to a care attendant for longer periods.

Observations and Conclusions

Scale of carers' need in London

The work of the projects indicates a massive level of unmet need for information, support and respite services among London carers. During the period of the scheme, projects contacted only a fraction of the carers in their borough. At a very conservative estimate, there were at least 5,000 carers in each borough.

The general picture is one of inadequate resources leading to rationing of services to carers. The assessment model used by most social services departments is inadequate, because it is wholly focused on the needs of the client and so doesn't allow carers to assert needs. In fact the model tends to reinforce carers' unjustified guilt that they don't do enough. It becomes a part of the rationing system, preventing rather than facilitating carers' access to services.

Access for minority ethnic carers is very inadequate, particularly for those who do not speak English or whose culture requires modification to 'mainstream' services. In particular the absence of appropriate respite services puts unacceptable levels of stress on these carers. This is an area which requires urgent action in every area where the programme generated data.

A way forward

Adequate services for carers require statutory authorities to allocate a little more funding for carers, and to spend it more creatively. The work of the eleven projects in the programme illustrates how much creative work of lasting value can be done, with the relatively modest sums available from Trust funders.

Quality services for carers are flexible, accessible and caring. These services are also likely to be the most cost-effective, because waste of resources is much reduced. A holistic model of working with carers (that is, taking account of all carers' needs) is a sound basis on which to provide appropriate and accessible services: the services which carers themselves want. These are the services which will genuinely support carers in continuing to care for their loved ones "in the community", and the evidence of the programme is that they will do so for extremely modest sums, particularly when compared to the costs of institutional care.

This should not however be confused with an attempt to provide all services through one agency in each borough. Local & health authorities already have statutory responsibilities towards carers, and voluntary sector efforts should continue to be bent on pressing these bodies to meet their obligations more adequately.

Reality dictates that there will continue to be a patchwork of provision for carers, in both statutory and voluntary sectors. Voluntary sector effort should be directed to developing this patchwork into a network, with clear, high quality information for carers about what they can get from whom. To reach all carers, information needs to be disseminated in the variety of ways illustrated in the body of this report, but on a wider scale.

Within each borough, there should be a single visible local contact point with an information/support/policy function, integrated with access work for minority ethnic carers. To fulfil its function, such a resource would need to have close links with an adequate number of appropriate direct access voluntary and statutory respite services, and good relations with statutory providers of other services.

Lessons for funders

Beyond the obvious messages that there are disturbing levels of unmet need among London's carers, and that their services are desperately under-resourced, the closer 'programme' relationship between funders and providers afforded some lessons about the process of funding.

An initial rigour with projects is productive in the quality of work done later; it is important to build in communication channels from the start. The funders' supportive approach when projects encountered difficulties paid dividends in establishing strong projects, most of which secured ongoing funding from other sources. Officers themselves benefitted from the greater learning opportunities resulting from increased contact.

That the level and terms of funding for development work should not in themselves restrict the work, is axiomatic. 100% funding frees the project from immediate survival concerns, and is appropriate for innovative work. The three year funding period, enlightened compared to year-by-year funding, was still found to be too short for some time-consuming development work. It ignores the necessity to set the work up, which in all cases took a period of one to two years. Five years therefore allows three years of developmental working time, and with particularly exacting work, such as access work with hard-to-reach minority ethnic communities, even ten years may be more realistic.

The final lesson of the scheme arises from the effectiveness of the partnership between funder and projects in meeting previously unmet need. It is possible to make a significant difference, even with relatively modest amounts of money. The Carers' programme made a difference.

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Project Details

AGE CONCERN ENFIELD:**Home Based Respite Service**

CPF grant: £168,478 over three years

Further information from: Tony Seagroats, Age Concern Enfield,
The Portacabin, Knights Lane, Edmonton,
London N9 OPD Tel: 0181 345 5577

AGE CONCERN WANDSWORTH:**Asian Carers Project**

CPF grant: £117,986 over three years

Further information from: Jane Turner, Age Concern
Wandsworth, 1c Yukon Road, Balham,
London SW12 9PZ Tel: 0181 675 7000

BRENT CARERS:**Advocacy and Support Service**

CPF grant: £123,690 over three years

Further information from: Julie Mallett, Brent Carers,
Middlesex House, Northwick Road, Wembley,
Middlesex HA0 1LF Tel: 0181 810 6660

BRENT TRIANGLE:**Overnight Respite and Support Services to Carers of Elderly Mentally Ill People**

CPF grant: £103,954 over three years

Further information from: Steven Attwood, Brent Triangle,
Unit 4, Strata House, 34A Waterloo Road,
London NW2 7UH Tel: 0181 450 2452

CARERS IN EALING:**Establishment of a Carers Forum**

CPF grant: £136,106 over three years

Further information from: Mr Lee Hewitson, Carers in Ealing
2nd Floor, Abacus House, 207-211 The Vale, Acton,
London W3 7QS Tel: 0181 749 0266

CONTACT A FAMILY:**Outreach Service for Parent Carers in three West London Boroughs**

CPF grant: £195,627 over three years

Further information from: Paul Soames, Contact a Family,
170 Tottenham Court Road, London W1P OHA
Tel: 0171 383 3555

CROSSROADS CARE ENFIELD:**Nightwatch Project**

CPF grant: £136,350 over three years

Further information from: Mr Seeva Velupillai, Crossroads Care Enfield, Community House, 311 Fore Street, Edmonton, London N9 OPZ Tel: 0181 373 6210

HARROW CROSSROADS:**Establishment of Care Attendant Scheme with an Outreach Service**

CPF grant: £160,000 over three years

Further information from: Jonathan McCafferty, Harrow Crossroads, 62 Pinner Green, Pinner, Middlesex HA5 2AB Tel: 0181 868 0903

HILLINGDON CARERS:**Asian Outreach and Development Initiative**

CPF grant: £152,729 over three years

Further information from: Caroline Leighton, Hillingdon Carers, 1st Floor, Luther Bouch House, 126 High Street, Uxbridge UB8 1JT Tel: 01895 811206

LONDON CHINESE HEALTH RESOURCE CENTRE:**Pilot Project to Establish Service for Chinese Carers**

CPF grant: £88,390 over three years

Further information from: Dr Pui Ling Li, London Chinese Health Resource Centre, Queens House, Leicester Place, Leicester Square, London WC2H 7BP Tel: 0171 287 0904

SUTTON CROSSROADS:**Holiday Respite Service**

CPF grant: £83,178 over three years

Further information from: Elizabeth Nielson, Sutton Crossroads, Sutton Carers Centre, 12-14 Benhill Avenue, Sutton, Surrey SM1 4DA Tel: 0181 661 9936