



**CARERS IMPACT**  
DEVELOPING MAINSTREAM SERVICES FOR CARERS



## **CARERS IMPACT**

The  
first  
**12**  
months

A REPORT ON  
WORK IN PROGRESS

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**MICHAEL POWELL  
PENNY KOCHER**



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The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.



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# Foreword

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What does community care mean to people at the sharp end, caring for elderly relatives or young disabled children, for example? Is it making any tangible difference to those who do the caring – often 24 hours a day and seven days a week? Making it work is about resources. It is also about attitudes: whether or not we treat carers as partners, recognising and supporting their essential role.

Carers Impact was set up to promote good practice, and change attitudes and priorities so that carers move to the centre stage. For it is only when policy-makers listen to their concerns, and give them the support and resources they need and deserve that community care will make a *real* difference.

*Winifred Tumim OBE JP*  
*Chair, Carers Impact Steering Group*

# Introduction

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The Carers Impact project is now 12 months into a three-year programme of work with health and local authorities in England, aimed at providing better practical support for carers as part of mainstream community care services.

This is our first report on work in progress and it sets out to achieve a number of things. Firstly, it provides a brief account of what Carers Impact is and how it works (Chapter 1). It then describes how far the project has progressed towards its goals over the past year, and gives a flavour of the fieldwork our development teams are undertaking with community care agencies (Chapter 2).

Perhaps most importantly, the report represents a first attempt to map out the key themes and issues that are emerging even at this relatively early stage in the project. These supply the main focus of the report and form the subject matter of Chapters 3 and 4. Our treatment of these issues is inevitably broad at this stage. However, as work with our project fieldsites extends in both range and depth over the next two years, we shall have much to say about: what community care agencies can do in practical terms to find more effective and appropriate ways of supporting carers; where the main blocks exist and how our fieldsites are overcoming them; and specific examples of good practice. Our main aim here is to flag up the issues which our development teams will be concentrating on as the work of Carers Impact progresses. A more detailed analysis will come in our subsequent reports and publications. The report concludes with a brief look at our future plans for the Carers Impact project (Chapter 5), and a summary of our strategy for evaluating both our development work in the field and the project as a whole (Chapter 6).

### **Who is the report for?**

We hope this report will provide useful and informative reading for a number of different target groups. In the first place, it will act as an initial progress marker for the project and a means of sharing information between the many people who are directly involved in the work of Carers Impact. These include project staff, Steering Group, our funders, the authorities and agencies working with us in the fieldsites, and the consultant advisers who make up our Carers Impact teams.

Secondly, many more sites and individuals have expressed an interest in Carers Impact than we are able to work directly with over our planned three-year lifespan. We intend this report to be part of our effort to help them to keep in touch with, and benefit from, the project.

Finally, we hope there is something of value here to people in all agencies who are interested in working towards the core community care objective of ensuring that service providers make practical support for carers a priority.

### *Acknowledgements*

Carers Impact would like to place on record its thanks to the local authorities, health authorities and other community care agencies that have invited the project to work with them in developing carer support. We also wish to record our appreciation of the enormous amount of hard work being undertaken by the people who are acting as consultant advisers on our Carers Impact teams. The success of the project largely rests on their experience, skills and expertise.

# Carers Impact – the project

## *The early days of Carers Impact*

Launched in October 1992, Carers Impact is a three-year project funded by the Department of Health, The Princess Royal Trust and The Gatsby Charitable Trust. It was conceived and planned by a national alliance representing health authorities, local authorities and the voluntary sector (see Appendix 3).

These national organisations came together, at the time of the delay in the implementation of the NHS and Community Care Act 1990, with a real determination to deliver practical support to carers. The question was *how*, as authorities and the voluntary sector are under enormous pressure to deliver services to a range of people in need, not just carers, in a culture of constant change.

The Carers Impact alliance came to the conclusion that the most fruitful way to enable authorities to deliver the services that carers so desperately need was for the project to work, not in a prescriptive way through instruction or guidelines, but through working in partnership with authorities in a developmental manner. As a result, the project has established a number of small multi-disciplinary development teams to work with health and local authorities in England. Each team comprises four advisers who have experience of bringing about change in carer support in their own sphere of work, and the skills to help others identify the issues and priorities in delivering practical services for carers. The advisers are senior managers, practitioners and development staff working in the statutory, voluntary and independent sectors who are seconded to the teams. Each development team always includes a carer.

## *The project's objectives*

Teams always begin with the situation on site, and work with health and local authorities in an enabling and interactive manner. This means that there is no one Carers Impact way of developing services. A team might help an authority to draw together a cross-agency, strategic carer policy, while another might help authorities with an operational policy for the delivery of services to carers. Teams might also give guidance on the involvement of carers, so that they can be asked about the practical support they want and their expertise used in designing better community care services.

Overall, the project's aims are to work in partnership with health and local authorities, stimulating initiatives which will provide greater practical support for carers within mainstream community care services. As well as working with health and local authorities directly, Carers Impact creates opportunities for authorities to learn from each other through workshops and conferences. The project will promote the adoption of good practice through highlighting the lessons learnt in project sites.

## *The project's values*

In addition to the above, all team members work within the framework of the project's core values, which are:

- ◆ the major role played by carers in supporting people in the community who are frail, ill or disabled should be recognised and valued;
- ◆ carers should have equal access to services regardless of age, gender, class, status or race;
- ◆ there should be equitable support for carers, whatever the illness or disability of the person for whom they are caring;
- ◆ carers should be consulted about their needs and preferences for services;
- ◆ service development affecting carers should be planned with carers;
- ◆ carers should take part in the evaluation of services.

## *The general developmental approach*

Carers Impact teams offer up to six days of consultancy and advisory support over one year. It is notable, however, that a pattern has emerged which indicates that teams are being used more and more for their process skills, helping the site think through their values and objectives rather than supplying advice and off-the-peg models from elsewhere.

Nevertheless, at the beginning, when the project staff make a preliminary visit, sites are offered a general developmental framework which has proved a useful start in most fieldsites. This framework has four stages:

- ◆ *Analysis of the current situation;* as a first step, this is an important task for senior managers of health and local authorities who have a remit to find out the health needs of the population. Carers Impact teams do not perform a detailed audit, but can assist the process by posing a number of questions: what do we know about the carers in the area; what services are provided for carers; what contacts are there with carers in the area; what do carers think of these services; what do carers say their needs are? In some sites teams have supplied feedback on current services, strengths and weaknesses, and carer participation.
- ◆ *Identification of the priorities for change;* this may include the team giving help in setting both the strategic and short-term agendas for improving carer support. In some sites, teams have provided carefully crafted workshops to help the local task force set its objectives. The emphasis is on what can be achieved within the next 12 months.
- ◆ *Implementation of change;* this involves supporting the local task force as work goes ahead to change and set up services for carers.
- ◆ *Review;* the emphasis is on teams and project staff helping fieldsites to identify and assess the changes that have taken place. The focus here is on practical outcomes for carers.

# 1

Overall, the ultimate aim for Carers Impact teams is to leave an enduring understanding and belief that partnership between carers and mainstream authorities can only lead to better services for both users and carers.

# Progress 1992/3

## *The launch*

By September 1992, Carers Impact had secured sufficient funding to send teams to approximately 15 sites within England. Its first task therefore was to alert health authorities (DHAs, FHSAs and RHAs), and local authorities and their provider units as to what could be gained from the project. On 30 October 1992, Carers Impact sent 1,400 leaflets to senior managers in health and local authorities. Advertisements to recruit consultant advisers for the Carers Impact teams were placed in key journals, a news release went out to over 40 press targets, and articles were written for several publications. As a result, over 50 authorities expressed an interest in working with a Carers Impact team, and nearly 400 people wanted to know more about becoming a consultant adviser.

## *Preparation of fieldsites*

### **First contacts**

The 50 authorities who approached the project office were sent detailed instructions on how to apply, which invited them to respond to a standard set of questions designed to elicit the kind of information we needed for selection purposes (see Appendix 4). This process has so far led to the submission of 30 bids for the support of a Carers Impact team.

For practical reasons, fieldwork is being phased in over the three-year period of the project so, while an immediate start was made to the preparation and selection process, applicants were informed that, if successful, not everyone would receive a team straight away.

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## Criteria for selection

In addition to providing developmental support to statutory and independent sector agencies in individual fieldsites, Carers Impact intends to draw on this work to identify general lessons which can be applied more widely. From this perspective, it is important to choose a group of fieldsites which display a range of different characteristics to allow development work to cover the spectrum of carers support issues. Choice of fieldsites was therefore not made on a 'first come first served' basis. Among the factors considered were:

- ◆ the need to work with a mix of localities that are at different stages of developing support for carers;
- ◆ achieving a reasonable geographical spread throughout England which includes a range of inner-city, suburban, provincial town and rural localities;
- ◆ developing a portfolio of work which covers a comprehensive range of carer support strategies and addresses the needs of different groups of carers;
- ◆ opportunities to work on ways of ensuring carer support is sensitive and responsive to the needs of Black communities.

## The authorities' contribution

The services of a development team are free of charge to participating authorities, but Carers Impact did expect that authorities would demonstrate:

- ◆ top-level commitment to improving services for carers;
- ◆ a commitment to consulting carers and involving them in planning and implementing service developments;
- ◆ a willingness to share experiences with other authorities at a regional and national level;
- ◆ a willingness to work co-operatively on support for carers with other statutory and voluntary authorities;
- ◆ a commitment to establish a local task force of local officers and carers to develop services for carers.

## The local task force

As a condition of becoming a Carers Impact fieldsite, localities were asked to identify key individuals from the main statutory and voluntary agencies to work with carers in a local task force. They had to be prepared to work together on developing services for carers and be the principal grouping alongside which the Carers Impact team would operate.

However, a group of committed individuals acting on their own cannot realistically prepare and implement a strategy for supporting carers. It is important that the task force:

- ◆ is linked into the local joint community care planning process;
- ◆ is representative of all the main agencies involved in commissioning and providing community care;
- ◆ contains people who can combine the role of carers' champion and be influential in strategic decision-making within the organisations they represent;
- ◆ works to build a vision of carer support both within the task force, and beyond to all the commissioning and provider agencies concerned;
- ◆ can solicit and maintain top management support for such a strategy;
- ◆ works to ensure that people at all levels in the agencies concerned are enabled to 'think carer'.

## Preliminary visits

Project staff began the process of selection with a preliminary visit to the majority of applicants. The visit had three main purposes: it allowed project staff to collect supplementary information and take soundings which went some way towards helping the final selection; it gave localities a chance to find out more about Carers Impact and the project's general approach; and it provided an opportunity to discuss in more detail the ways both Carers Impact and the locality might work together. Project staff found that one

of the key objectives in this preliminary stage was building the local task force.

### **Final selection**

Both the applications and reports written by the staff were read by a 'selection panel' made up from members of Carers Impact Steering Group. Difficult choices had to be made but, after careful consideration, with close attention paid to the above-listed criteria for selection, in April 1993 teams were allocated to Sheffield Health Authority, Northampton Social Services, and a combined bid from Dorset Health Commission and Dorset Social Services. In September 1993, a further three sites began working with Carers Impact teams, while, at the end of the year, four more sites will bring the total of teams allocated in 1993 to ten (see Appendix 1). Figure 1 gives a basic overview of the current focus of work in the first six sites.

**Figure 1 The first six fieldsites**

Location	Core agencies involved	Current focus of Carers Impact support
<i>Tranche 1</i>		
Dorset	Dorset Health Commission Dorset Social Services	Working with a newly formed cross-agency, county-wide Carers Development Group and assisting the process of implementing the Wessex Regional Health Authority's policy document 'Think Carer'.
Northampton	Northants Social Services Kettering Health Authority Northampton Health Authority Northants FHSAs Northants Council for the Disabled	Working with a newly formed Carers' Strategy Group (CSG) for the county and assisting in the process of developing an inter-agency strategy for carers support. Also supporting the CSG in the following priority areas: developing a carers' forum; working with primary care providers to identify carers; meeting the practical training needs of carers; and encouraging professionals at all levels to 'think carer'.
Sheffield	Sheffield Health Authority Sheffield Family & Community Services	Working with a newly formed Sheffield Core Group to establish a city-wide carers' strategy. There is a strong commitment to working jointly to purchase and provide a more coherent service for carers. Particular areas of interest are consulting and involving carers, informing carers of the services available to them, and the new carers' centre funded by The Princess Royal Trust.

**Figure 1 (cont.)**

Location	Core agencies involved	Current focus of Carers Impact support
<i>Tranche 2</i>		
London Borough of Havering	Havering Social Services Havering FHSAs & DHA	A local Project Group has been set up linked to Havering's joint planning process. It includes representatives from local parent groups, purchasers and providers of the main community care agencies. The team is helping the Project Group to set some achievable targets for the next 12 months to support parent carers in the London Borough of Havering. There is a strong commitment to involving parents and determination to achieve practical results.
Hereford & Worcester	Hereford & Worcester Social Services Age Concern FHSAs & DHAs in the county	Providing developmental support to an established Carers Service Development Group for the county. Four priority areas for improving services to carers have been selected. The Carers Impact team is facilitating the process of identifying specific objectives and action plans in the four areas and will support service development work and evaluation of the outcomes.
Wigan	Wigan Social Services Wigan & Leigh Pensioners' Link Wigan Health Authority	A local task force has been assembled which represents purchasers, providers and carer interests at all levels. Its task is to review current services for carers in the Metropolitan Borough of Wigan, and to tackle service improvements especially in the areas of information and carer involvement. There is a commitment to involve local carers in all aspects of this work and a strong emphasis on achieving practical outcomes.

## *The Carers Impact teams*

### **Composition of the team**

Each team comprises four consultant advisers whose main role is to help others identify priorities and find solutions to problems in delivering services. Teams include people with specific expertise in developing services for carers. Consultant advisers are drawn from a range of backgrounds: health, local authority, voluntary agency or caring; and a mix of professional and managerial levels. The team is carefully matched to the specific needs of the fieldsite.

Every team includes a carer. The role of the carer within the team is crucial. Each consultant adviser is experienced in his or her own way, but carers, through their direct experience of caring, focus the attention of the team on to the kind of issues that are central to the project. This hands-on knowledge of caring brings an expertise to the teams that only carers can provide.

### **Recruitment**

Carers were recruited through articles in a number of carer and voluntary sector journals, and through word of mouth via numerous contacts, including Carers National regional workers. The response revealed a number of active carers who were also experienced in negotiating and working with senior managers of health and local authorities. All members of Carers Impact teams receive a sessional fee (paid either directly or to their employing agencies as appropriate). In addition, consultant advisers who are also carers are reimbursed the cost of providing alternative care so that they are free to work with teams on site.

Senior managers, practitioners and development staff were recruited through advertisements in the key professional journals.

## **Preparation of consultant advisers**

Out of 400 enquiries, 30 applicants (including eight carers), interested in becoming consultant advisers, attended a preparatory workshop at the King's Fund Centre in January 1993. The workshop was designed as a forum for people to find out more about Carers Impact, its current work and its methods. It was also an opportunity for applicants and project staff to explore whether working for Carers Impact was for them. People were aware that selection of consultant advisers to form Carers Impact teams would take place following the workshop.

Feedback was constructive and helped project staff in the planning of a second preparatory workshop, held in September 1993, in which 36 applicants participated. Consequently, we currently have a 'pool' of approximately 60 consultant advisers from which we are forming teams to work in specific sites.

## **Carers Impact briefings**

Carers Impact consultant advisers have access to a number of Carers Impact briefings. These are working documents designed to act as guidance to advisers, which include our value statement and a variety of papers on issues connected with the development of services to carers. They give insight to new advisers into how Carers Impact teams might work in partnership with health and local authorities, and they also act as a benchmark once teams are in the field.

Initial feedback on the value of these briefings has been extremely positive and we have recognised their potential usefulness to other people who are working on the development of services for carers. We are continuing to refine the briefings and extend the range of issues they cover. We intend to publish the full set in due course.

# Carer-sensitive community care

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## *Introduction*

The first three Carers Impact teams started work in the field in May 1993. At the time of writing, these teams had been working with their client authorities for approximately five months. In addition, the second tranche of fieldwork was just beginning with a further three teams making first site visits in September/October.

Carers Impact fieldwork is therefore still at an early stage. Nevertheless, some common themes are already emerging which we shall describe in this section of the report. This will set the scene for a consideration of some key issues our fieldsites are currently facing as they work on improving carer support. These issues are the subject of the next section.

## *Common themes*

Across the country, the provision of practical support for carers by community care agencies is extremely patchy and, until now, has often been treated as a low priority by most local and health authorities, if indeed it has been seen as a priority at all. Many established carer support initiatives are poorly and insecurely funded (e.g. with short-term joint finance and no guarantee of longer-term funding). Moreover, many schemes tend to be shaped by what the provider deems it appropriate to offer to carers, rather than what carers say they want or prefer. This picture will be immediately recognisable to most people, especially carers themselves.

# 3

## **Shifts in attitude, thinking and service delivery**

Success in achieving substantial improvements in practical support for carers is not a simple matter. It is widely recognised that it will involve agencies making significant shifts in:

- ◆ attitude
- ◆ thinking about priorities
- ◆ the way services are delivered.

The movement from provider-led to user and carer needs-led services is one dimension of this. Reversing the marginalisation of carers in mainstream community care services is another.

## **Joint strategies and carer involvement**

Carers Impact experience suggests that the process of agencies working together, with the active participation of carers, to create a joint strategy for carer support is an essential element in achieving the above shifts. It provides a framework for change in the following key areas:

- ◆ no one agency can provide the full range of services and flexibility of support that carers need – effective collaboration between statutory, voluntary and independent sector agencies is therefore a fundamental requirement;
- ◆ it encourages agencies to focus on how carers fit into their vision of what good community care should look like (and if they have not already recognised the need to work on that vision, the process of developing a strategic response to carer needs can be a fruitful starting point);
- ◆ taking the opportunity to involve carers in fresh strategic thinking is an important step in starting the shift from provider-led community care to user needs-led services – it begins to transform rhetoric into action.

## What do we mean by 'strategy'?

We have talked about the process of developing a joint carers' strategy, but what exactly do we mean by 'strategy'? Strategies can take many different forms and, indeed, experience in various fields tells us that the quality of the process used to build a strategy is usually more important than the final content of any document. However, if a carers' strategy is to mean anything at all, it needs to encompass a number of basic elements.

### *Values*

It needs to express with some clarity the beliefs which underpin the thinking behind the strategy. In particular, shared values concerning: the carer's role; carers' rights as citizens; the roles of statutory and voluntary organisations in community care; and the nature of the services and support that carers are entitled to expect. A statement of more universal values about equity, access, choice, equality, and user involvement is also likely to be important.

### *Policy statement*

An explanation of the general policy that is to be adopted towards the provision of services and support to carers, and how these will be delivered. Many agencies are adopting a 'carers' charter' approach to this.

### *Goals*

A strategy means little unless it contains specific goals and a clear indication of intended outcomes. It should make clear exactly what improvements to the lives of carers are being sought and set a timescale.

### *Measures of achievement*

How is success in attaining the stated goals to be measured? This should, as far as possible, include measures of outcome as well as process and outputs. The involvement of carers in monitoring and evaluation should be a key consideration.

# Emerging issues

## *Introduction*

All of our current sites are grappling with the complexities of making the shift from provider-led to carer-sensitive community care. As Carers Impact teams work alongside them, several key issues are starting to emerge which we explore in this section of the report. In the main, these are process issues, that is they are principally concerned with *how* to make the shift happen. What is also apparent is that there are still fundamental questions to be answered about the attitudes of statutory and voluntary agencies towards carers and the roles they perform, and it is with this issue that we begin.

## *Establishing a 'win-win' relationship with carers*

Most agencies by now appear to have at least taken on board the notion that developing services that are led by the needs of service users and carers involves radically new approaches to consultation and user/carers participation. Our specific interest here, of course, lies in carer participation. What many agencies sometimes overlook is that for carer participation to work, and to go on working, both they and their local carers must be able to derive something of value from the process. This is what we mean by applying the notion of 'win-win' in this context.

Most community care agencies are in practice still relatively unfamiliar with this new style of participation and lack confidence in handling it. Many are not clear about what they themselves hope to gain from increased carer participation, and often harbour significant fears about possible adverse consequences. For example, questions like 'will we raise false expectations?', or 'are we going to be swamped by demands we cannot meet?', express the kinds of anxiety frequently encountered in our fieldwork.

Despite this, there is much encouraging evidence to suggest that once agencies do summon up the courage to take a plunge in these uncharted waters and find that they can actually swim, these sorts of fears rapidly fall into perspective as the potential gains of increasing participation become clearer.

While many agencies remain unclear about how they can benefit from carer participation, it is also the case that carers are uncertain, not to say sceptical, about whether it is worth the investment of their time and effort. Negative feelings about the kinds of 'consultation' that have taken place in the past may only serve to increase the sense of cynicism.

A fundamental step in building the essential 'win-win' relationship involves agencies exploring and testing their underlying assumptions and attitudes towards carers. This task is complicated by the fact that carers stand in such an ambivalent relationship with health and social care providers. Twigg<sup>1</sup> has drawn attention to this important issue and suggests that service providers see carers in several different ways:

- ◆ carers as a resource to be exploited
- ◆ carers as partners in providing care
- ◆ carers as clients in their own right
- ◆ carers as barriers to independent living ('superseded carers').

The attitudes of service providers are likely to be shaped by all of these ways of seeing carers, each of which may be predominant at different times and in different circumstances. Agencies that have not consciously explored, and come to terms with, this conflict will find that it stands in the way of creating the open approaches that are needed to ensure effective consultation and the active involvement of carers in service development.

Carers Impact teams are encountering a number of blocks in this area. So what is to be done? Our experience so far suggests that the following approaches are likely to be helpful:

- ◆ agencies benefit considerably from opportunities to think through their attitudes towards carers and caring. This should be an essential part of the process of building a corporate vision of what good community care looks like;
- ◆ how do agencies see carers and how do carers see them? This is a vital question for all community care agencies to explore. It is best tackled by setting up opportunities to talk with carers and carers' groups in an environment that is 'safe' for all parties and conducive to open dialogue. This not only allows mutual attitudes and expectations to be explored but, if properly facilitated, can open the door to a sustained dialogue which forms the basis of true participation;
- ◆ agencies should guard against allowing uncertainties, ambivalence of attitudes, feelings of vulnerability, and anxieties about giving up a little power, stand in the way of efforts to create an open dialogue with carers. This is about building confidence and trust on both sides, and can only be achieved by agencies demonstrating that they want to talk and work with carers on equal terms.

### *Involving carers*

It follows from the above that learning how to work effectively with carers, and finding appropriate and realistic ways of involving them both individually and collectively in planning and developing services, are key tasks for community care agencies. Many agencies are still near the bottom of a steep learning curve in this respect, and it is therefore not surprising that most applications for developmental support received by Carers Impact include a request for assistance and advice in this area.

Carer involvement is an activity that will benefit from the identification and dissemination of good practice. This is something to which we intend to devote significant attention based on the growing experience of our teams. In their advisory role, Carers Impact teams are drawing on the collective knowledge of their members in responding to the many requests

they receive to provide examples of how carer consultation and involvement has been developed elsewhere. In addition, there are a number of published texts on this subject which we have found extremely useful.<sup>2,3,4</sup>

Nevertheless it is not simply a question of applying off-the-shelf models, useful though tried and tested approaches are. Models have to be adapted to fit circumstances that may differ considerably between localities. Equally, the process of clarifying attitudes and expectations, as discussed above, is something that has to be worked through everywhere.

Our teams are finding that they need to tread a careful line which balances responding to client requests for tested examples of 'how to do it' and encouraging experimentation with a range of different approaches to promoting carer involvement. Helping their clients to circumvent some of the pitfalls is another role which teams are trying to perform. These pitfalls include:

- ◆ *Tokenism* – It simply is not enough to find one or two interested carers who are willing to be appointed to joint planning groups or project steering groups and call that 'carer involvement'. Our experience is that many agencies are still locked into this mode of thinking.
- ◆ *The myth of the 'representative carer'* – We hear agencies lamenting the fact that the carers invited to attend meetings or forums speak about their own individual experiences and situations, rather than representing the views of a broad constituency of carers. The simple fact is that the demands of caring prevent most carers from organising themselves in democratically constituted bodies that are capable of speaking with a collective carer voice. If agencies really want to listen to the carers' voice, then they have to develop a more sophisticated approach and adopt a range of methods for encouraging the participation of individual carers as well as established carer groups, until a reasonably wide spectrum of opinion is tapped.
- ◆ *Regarding consultation as a 'one-off' activity* – Effectively harnessing the views and expertise of carers and users demands a structured process which permeates all levels of

service management. It therefore involves a multiplicity of approaches potentially involving staff at all levels in community care agencies. Needs-led services can only be achieved if carer (and user) involvement is realised in:

- (i) planning service developments
- (ii) drawing up service specifications
- (iii) designing and managing care packages for individual clients

- (iv) evaluating the quality of services.

Current involvement of carers is frequently limited to only one or two of the above activities (if it exists at all) and is often treated as a one-off exercise to meet the formal requirements of the annual community care planning-cycle rather than as a continuous process.

- ♦ *Failure to break the mould of traditional consultation procedures* – Agencies sometimes express concern that their usual methods of consultation on plans and service developments produce responses from only a handful of carers or carers' groups. They are right to worry about this because it demonstrates that the traditional methods are failing. Stronger carer participation can only be achieved through a range of complementary initiatives which could, for example, include all of the following (and more):

- (i) carers' forums
- (ii) focus groups
- (iii) individual care worker/client contacts
- (iv) postal surveys
- (v) interview-based surveys
- (vi) neighbourhood forums
- (vii) drop-in centres
- (viii) carer representation on planning groups
- (ix) phone-in consumer response lines.

Expanding the number and types of methods used increases the range and, therefore representativeness, of the carers' voice that is heard.

## *Building commitment to supporting carers within community care agencies*

All Carers Impact fieldsites were asked at the outset to identify key individuals with a lead responsibility for developing carer support. These people were to be drawn from the main statutory and voluntary agencies concerned with commissioning and providing community care services. We also specified that they should be prepared to work together, and with active carer involvement, to improve practical support for carers as part of local community care strategies.

In effect, we asked our sites to establish a carers' support task force (if an equivalent group did not already exist) which would serve as the focal point for service development and be the principal grouping alongside which the Carers Impact team would operate.

Experience in working with this model has not led us to question its validity. From the outset, however, we were aware that the establishment of a committed task force could not guarantee the full corporate commitment of the agencies involved.

Whether these local task forces are established as formal strategy and/or service development groups, or constitute a more *ad hoc* and informal arrangement (and there is considerable variation between the first six Carers Impact sites), they must be capable of exerting a strong influence at all levels in the relevant agencies. To achieve this they have to increase carer awareness and build a strong corporate commitment to improving support for carers which extends from top management down to each and every fieldworker.

Our experience so far has highlighted a number of important requirements:

- ♦ the people selected to join the task force are very important. Individual members need to combine a grasp of carers' issues with an understanding of the community care reforms and how these are managed within their own agencies. The group must include people who are capable of influencing

the process of strategic management within agencies in order to stimulate the important shifts in thinking and attitudes referred to earlier;

- ♦ the task force also needs people who can act as change agents at various levels by raising carer awareness and helping colleagues to recognise the potential contribution they can make to improving practical support to carers. These are people with vision, commitment to carers, enthusiasm and energy;
- ♦ the task force is likely to be the place where a clear vision is first generated of what needs to be done in order to maximise practical support for carers. One of the most important tasks of the group is to be constantly active in trying to 'sell' their vision to the agencies they represent and, indeed, to any other agency that has a part to play in supporting carers;
- ♦ the group must avoid becoming too introspective. It must continually test its ideas and plans through regular contact with managers, professionals and workers at all levels, as well as through active partnership with local carers. Raising awareness of carers, engendering a debate about their needs and preferences concerning services and support, and ensuring that carers occupy their rightful place on the community care agenda, are all necessary outcomes;
- ♦ gaining an input into staff training and continuing professional education programmes is an excellent way of encouraging staff at all levels to 'think carer'. Carers Impact teams have come across a number of notable examples of good use being made of this approach, including the use of carers as tutors on educational programmes.

### *Working across agencies*

Carers' needs for services and support do not fall into neat health, social or welfare benefit categories. Potentially, they span the whole spectrum of community care provision and, while carers are naturally little interested in who provides a particular service, it is essential that agencies work together to provide the services that carers need.

The implementation of the Community Care Act has forced many statutory agencies to rethink their collaborative arrangements, both with other statutory agencies and with the voluntary and independent sectors. In many instances, this fresh approach and increased sense of purpose appear to be yielding positive results. People in a number of Carers Impact fieldsites have said to us that this renewed interest in collaboration was an important factor in creating enough momentum to carry on and collaboratively tackle carers' issues.

While some encouragement can be drawn from this, it is also evident that the strength and the quality of collaborative arrangements vary considerably around the country. Progress in this, as so much else, is very patchy. In the fieldsites, Carers Impact cannot hope to influence the whole gamut of inter-agency relations, but since improved mainstream support for carers depends so much on effective collaboration, it will undoubtedly remain an important focus of attention throughout the project.

### **The role of lead agencies**

As the designated lead agency for community care, it is not surprising that the initiative to invite in Carers Impact came from Social Services in the majority, but by no means all, of our fieldsites. A strong lead clearly has its advantages in establishing an agenda and getting things moving, but in terms of facilitating good inter-agency working, Social Services Departments (or other agencies taking the lead) must be careful not to overstep the mark. Effective collaboration is fostered by a degree of sharing, particularly in the areas of power, resources, responsibility and ownership. Ownership of responsibility for supporting carers is a key issue in many of the fieldsites. In the early stages of work, a number of our teams are paying particular attention to the need to work with their clients to ensure that all the relevant agencies are on board and taking an active interest.

## Negotiating joint goals

A necessary part of the process of achieving joint ownership is the negotiation of joint goals and a joint agenda for improving carer support. This reinforces the importance of agencies working together with local carers to produce a joint strategy. When dealing with so many stakeholders, it is important not to underestimate the complexities of this process and the significant investment of time and effort that is required.

### External facilitation

It is apparent that in some of the fieldsites, the process of becoming involved in the Carers Impact project has acted as a catalyst in bringing together new or stronger inter-agency groupings to work on carers' issues. In some places, the Carers Impact teams are actively being used to facilitate the business of working across agencies. The fact that developmental assistance is being sought in this area may suggest that more widely available forms of external facilitation could be useful to agencies in strengthening collaboration across the whole range of community care activity. It is obviously beyond the scope of Carers Impact's remit to try and meet this need, but we hope to form a clearer picture of what is required.

### *Bottom-up/top-down service development*

The final set of issues is very much concerned with the process of developing a joint strategy for carer support which will command support not only among community care agencies but from local carers themselves. In this respect, a carers' strategy differs little from other strategies, and so the issues will apply equally to other aspects of community care.

The crucial point here concerns the overall approach to be adopted. Consultation with carers about how they see their needs and preferences for services has to shape and guide the development of strategy. So do the lessons learned from practical

service development initiatives with and for carers on the ground. Conversely, the formulation of a strategic framework helps to prioritise objectives, and focus effort and resources where they can achieve the greatest effect.

Work needs to be progressed simultaneously at both ends of the continuum, and this is what we mean by a bottom-up/top-down approach. The balance is a dynamic one and is vital in keeping momentum and commitment flowing among all the stakeholders. For example, maintaining the interest and involvement of carers in developing a strategic response to their support needs will depend on being able to demonstrate that things can start to change on the ground now, and not at some vaguely specified date in the future. Likewise, early practical gains and tangible short-term achievements are an important factor in keeping up the enthusiasm and commitment of staff in community care agencies upon whose efforts longer-term change will depend.

All of this may sound obvious, but how familiar still is the sight of 'strategic planning blight', where the decision to develop a long-term strategy is taken as the signal, whether intended or not, to cease all practical developments on the ground until a new course is set from the top! This is a pitfall to be avoided at all costs. Carers Impact teams are finding that they need to be vigilant in monitoring and feeding back to their clients how well this delicate balance between bottom-up and top-down initiatives is being maintained.

The emphasis on developing a strategic response to carers' support needs, currently the dominant feature of Carers Impact fieldwork, feels like the right approach at this time. However, we must not allow ourselves to become so preoccupied with strategy that we overlook the importance of, firstly, learning from what already exists (or does not exist) for carers on the ground; and secondly, continuing to nurture practical service developments, with the active involvement of carers, that will help give shape to the strategic direction and build everyone's confidence in our ability to create a better future for carers.

## References

- 1 Twigg J. Carers research and practice. London: HMSO, 1992.
- 2 National Institute of Social Work. User-centred Services Group. Building bridges between people who use and people who provide services. London: NISW, 1993.
- 3 Office for Public Management. Initiatives in user and carer involvement: A survey of local authorities. Occasional Paper No. 4, London: OPM, 1993.
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# Future programme

## *Fieldwork*

Work will continue in the sites established in 1993. A final tranche of new fieldsites will be working with Carers Impact teams by May 1994. The exact number is still to be decided.

The diversity of developmental help which is one of Carers Impact's key strengths will also continue. Some Carers Impact teams will be involved in helping the local task force draw in key funders, while other teams will be concerned with helping task forces spread their vision of the prime importance of supporting carers. Overall, our emphasis will be on reinforcing and maintaining the shift in attitude that is needed to make mainstream services more sensitive to carers.

## *Dissemination of lessons from fieldwork*

As early tranches of fieldwork near completion, the emphasis of the Carers Impact project will move to the wider dissemination of the lessons learned through the work of our teams. Throughout 1994 we will aim to:

- ♦ provide practical examples of successful service developments;
- ♦ document difficulties and how to overcome them constructively so that others can learn from them;
- ♦ draw general policy lessons about Carers Impact's achievements and the implications for developing services for carers;
- ♦ generate country-wide interest and enthusiasm about developing services for carers.

Dissemination will take place at two levels:

- ◆ between Carers Impact fieldsites;
- ◆ to a wider potential audience of all community care agencies in England.

### **Strategies**

Carers Impact will aim to reach the individuals, professionals and organisations within fieldsites and the community care agencies through a variety of means, including the following.

#### *Fieldsite workshops*

Building on a model tested in October 1993, Carers Impact will hold at least two further fieldsite workshops concentrating on the carer support issues being tackled in the second and third tranche sites.

#### *National/regional conferences and workshops*

In the autumn/winter of 1994 we plan to hold at least two, possibly more, larger conference or workshop events. These will open up to a wider audience lessons learned from Carers Impact work in the field, and focus more clearly on good practice in carer support. The idea of building strong alliances between community care agencies and carers has been a central theme in all aspects of Carers Impact activity, and we want to see this clearly reflected in the content and format of these events.

#### *'Carers Impact: A Report on Work in Progress 2'*

A second report on work in progress will be published by the end of 1994. Again, this will convey key messages from development work in the fieldsites, and will be able to draw on the evaluation of the development work completed in the first and second tranche sites.

#### *Other publications*

During 1994 we shall be considering the publication of other materials based on Carers Impact work. It is more than likely, for instance, that we will publish the Carers Impact briefings, originally prepared as guidance notes for our consultant advisers. These are a growing series of briefing papers on improving practical support for carers and the developmental approach of Carers Impact. Feedback already received indicates that these briefings have a wider relevance and application. In an edited form, they are likely to be a useful tool for community care agencies.

#### *The future of Carers Impact*

Current plans for the Carers Impact project include a developmental work schedule that will carry on until mid-1995. Grant funding for the project is assured until that time. During the course of 1994, discussions will be held with the Project Steering Group to determine whether there is a case for the Carers Impact initiative to continue in either its present or some revised form beyond mid-1995.

Part of that discussion will take into consideration that, after 1995, there will exist a pool of up to 60 highly skilled consultant advisers experienced in assisting authorities to develop their support for carers. One question needing to be answered will be how this expertise can continue to be used. If it is decided to continue the project, arrangements will be made to draw up detailed future plans and a new funding strategy. Alternatively, if it is decided to wind down the project, we shall make plans to complete the internal project evaluation and write a final report.

# Evaluation

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## *Introduction*

An internal evaluation plan has been developed for the Carers Impact project. This evaluation, which is to be mainly qualitative in nature, will operate at two levels: fieldsite and project.

### **Fieldsite**

An integral part of the developmental assistance offered by Carers Impact teams is help with evaluating the effect of local service development initiatives on the lives of carers. Teams are approaching this task by first of all helping their clients develop clearly stated objectives for each piece of work that is undertaken to develop services and/or support. As far as possible, we believe these objectives should be expressed in terms of desired outcomes for carers. The involvement of carers themselves in defining what these outcomes should be is an important part of the process.

As work progresses with service developments, our teams encourage sites to define measures for assessing progress towards the specified objectives. In practice, we aim to help sites use a mixture of process measures and direct measurement of outcomes, the latter usually through assessing carer satisfaction with changes made to services in the community.

Practical evaluation at this level is, we believe, important in enabling our clients to learn from the process of developing services so that conclusions can be drawn which will be useful in planning and implementing future change in services to carers.

## Project

As with the fieldsites, our starting point for thinking about the evaluation of Carers Impact as a project was to define clearly what we considered our overall objectives to be. The Carers Impact Steering Group adopted the view that the principal goal of the project is to improve the quality of life of carers. The specific contributions we hope to make to achieving this are:

- ◆ to help statutory agencies implement improvements in mainstream community care services that will contribute to a better quality of life for carers;
- ◆ to learn how to achieve change which will promote improvements in mainstream carer support and devise ways of sharing this knowledge with as many community care agencies as possible.

It will be seen from this that the two levels of evaluation (fieldsite and project) we are proposing to carry out are closely interrelated.

## *What information are we collecting?*

In order to carry out a basic evaluation we have decided to collect three sets of information:

### **I Information about local carer needs and preferences**

This includes:

- ◆ How are agencies applying national research on carers and carer needs in the local situation?
- ◆ What methods are being used to establish a dialogue with carers?
- ◆ How successful are these methods in making contact with the various groups of carers?
- ◆ What information is this dialogue yielding on the needs and preferences of carers?

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- ◆ What use is made of this information?
- ◆ What impact does the information have on the planning and design of services?
- ◆ How are carers involved in the community care planning process?
- ◆ What influence do their views and comments have?
- ◆ What does carer feedback tell agencies about the quality and appropriateness of carer support?

## **2 Developing support for carers – use of explicit service objectives and the assessment of outcomes for carers**

This subject has been referred to already. Specifically, the kinds of information we are encouraging our sites to supply are:

- ◆ a description of each piece of service development work undertaken;
- ◆ a clear statement of service development objectives;
- ◆ an explanation of how these objectives relate to the identified needs and preferences of carers;
- ◆ how the satisfaction of both service user and carer needs are reconciled (especially where different or conflicting needs are apparent);
- ◆ the measures used to assess the effectiveness of planned changes in services in achieving stated objectives, and what the outcomes are;
- ◆ how carers are involved in assessing these outcomes and the use that is made of the resulting information.

## **3 Documenting shifts towards carer-sensitive services and the factors which promote and hinder these shifts**

We are trying to look at four sets of issues here:

- ◆ how community care agencies are developing a new relationship with carers (and users);
- ◆ how carers are involved in decisions about services at all levels;
- ◆ whether statutory agencies are actually changing the way they work;
- ◆ ways of providing resources to enable carers and users, and their organisations to participate.

### *Methods of information collection*

We are collecting the above information in three principal ways:

- ◆ documentation of the joint work undertaken by Carers Impact teams and their client agencies;
- ◆ reflective diaries maintained by Carers Impact consultant advisers working in the field (recognising the crucial role played by our advisers as participating observers);
- ◆ simple questionnaire-based surveys. These are being designed to elicit opinions and feelings about the changes that occur in the fieldsites with regard to attitudes and practice in carer support, and what brings those changes about. Surveys will be undertaken at the end of each Carers Impact team field assignment.

*Further information on our evaluation methodology can be obtained from Carers Impact project staff.*

## APPENDIX I

# Fieldsites – 1993

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*Tranche 1* (Commenced work in May 1993)

Northamptonshire  
Dorset  
Sheffield

*Tranche 2* (Commenced work in September 1993)

Hereford & Worcester  
London Borough of Havering  
Wigan

*Tranche 3* (To commence work in December 1993)

Plymouth & Torbay  
Kingston-upon-Thames  
Thameside Mental Health (Basildon & Thurrock)  
Gloucestershire

## APPENDIX 2

# Consultant advisers – tranche 1 and 2

Jean Atkinson	Localities Co-ordinator, SE London Commissioning Agency
Ruth Bailey	Carer, West Midlands and Vice-Chair of local branch of Multiple Sclerosis Society
Charlie Barker	Assistant Director, Tameside Social Services
Audrey Chamberlain	Adviser, Community Development, North and Mid-Hampshire Health Commission
Mary Colato	Co-ordinator, East Sussex Care for the Carers Council
Brenda Crosby	Carer, Lancashire, founder member of the Fylde Coast Branch of Carers National Association and member of the National Management Committee of Carers National
Maria Duggan	Freelance consultant (Community Care), North London (formerly a Project Officer, King's Fund Centre Carers Programme)
Peter Frost	Carer, Vice-Chair, East Sussex Care for the Carers Council, and Lecturer at Brighton University
Pat Gay	Freelance consultant, Newmarket. (Background in research and community work)
Kate Griffiths	Head of Carers Unit, Birmingham City Council

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Julia Hassall	Community Services Manager, Humberside Social Services
Mike Hatch	Disabled Persons Act Social Worker, Gloucestershire
Ann Kemp	Assistant Director, Primary Care Services, Nottingham Community Health
Pamela Mason	Carer, East Sussex, freelance consultant and Chair of East Sussex Care for the Carers Council
Denise Mawby	Senior Health Education Officer, Kettering Health Authority
Sandra Miln thorpe	Carer, Berkshire
Barry Palmer	Freelance consultant, Worcester
Steve Royston	Contracts Manager, East Sussex Social Services
Sheila Taylor	Principal Services Officer (Commissioning), Oxford Social Services (formerly Programme Co-ordinator of the Oxfordshire Carers Unit)
Monica Unwin	Assistant Director (Development), Alzheimer's Disease Society
Jacqui Wharrad	South East Regional Officer, Crossroads
Marlene Winfield	Independent consultant and policy analyst
Sylvia Wiseman	Carer and Chair of 'Carers Support in Brent', North London

## APPENDIX 3

# Steering Group membership, and project staff

Carers Impact is steered by a national alliance representing health authorities, local authorities, community care management and the voluntary sector which came together to focus attention on developing support for carers as part of the national community care initiative.

The Carers Impact Steering Group is chaired by Winifred Tumim OBE JP, and actively supported by the following organisations and their representatives:

Department of Health Jane Allberry (until June 1993),  
replaced by Anne Thyer

The Gatsby Charitable Trust Janet Morgan

The Princess Royal Trust  
for Carers Colin Williams

Association of County Councils Stephen Campbell

Association of Directors of  
Social Services Ian White

Association of Metropolitan  
Authorities Brian Jones

Carers National Association Jill Pitkeathley

Contact a Family Harry Marsh

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Crossroads Care	Ian Croft (until June 1993), replacement to be announced
Institute of Health Services Management	Pamela Charlwood (until April 1993), replacement to be announced
The King's Fund Centre	Janice Robinson
National Association of Health Authorities and Trusts	Derek Day (until December 1992), replaced by Chris Vellenoweth
Social Services Inspectorate	Judy Downey (until June 1993), replaced by Amanda Edwards

### **Project staff**

Project Manager	Michael Powell
Project Officer	Penny Kocher
Project Secretary	Caroline Hunter

The Carers Impact project is based at The King's Fund Centre in London.

## APPENDIX 4

# Information to support request for developmental assistance

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### **(a) Self-assessment against standard criteria**

We shall be evaluating all applications against the following criteria and we would like you to consider where your authority stands in relation to these.

- (a) Statutory agencies should demonstrate evidence of a top-level commitment to developing community care services which take account of carer needs and provide improved support for carers.
- (b) Applicants should be willing to work co-operatively with other statutory agencies, voluntary agencies, and the independent sector in developing carer support.
- (c) Carers Impact will operate by working alongside a group of local officers who are allotted responsibility for developing health and social care support for carers (either specifically or as part of a wider set of responsibilities for community care development). This group should be capable of working across agency boundaries. If not already established, we shall be looking for a commitment to set up such a group.
- (d) A commitment to consulting carers and involving them in planning and implementing service developments.

(e) Involvement of both purchaser and provider interests in developing carer support.

*Please tell us how your authority measures up against these criteria.*

**(b) Community care plan**

*Please provide us with a copy of the current Community Care Plan for your area.*

**(c) Specific questions**

*Please respond concisely to the following questions:*

- (a) Does your organisation have a policy statement about supporting carers and/or involving carers in needs assessment, and the planning and delivery of services? If so, please send us a copy.
- (b) What action has your organisation taken in the last five years to improve services and support for carers?
- (c) Does your organisation have any immediate plans for improving carer support? If so, please describe.
- (d) What arrangements have you adopted locally for working jointly with other statutory agencies and the voluntary/independent sector to plan and develop community care? Have these been used to work on improving carer support?
- (e) How do you think Carers Impact can help you?

**(d) Local contacts**

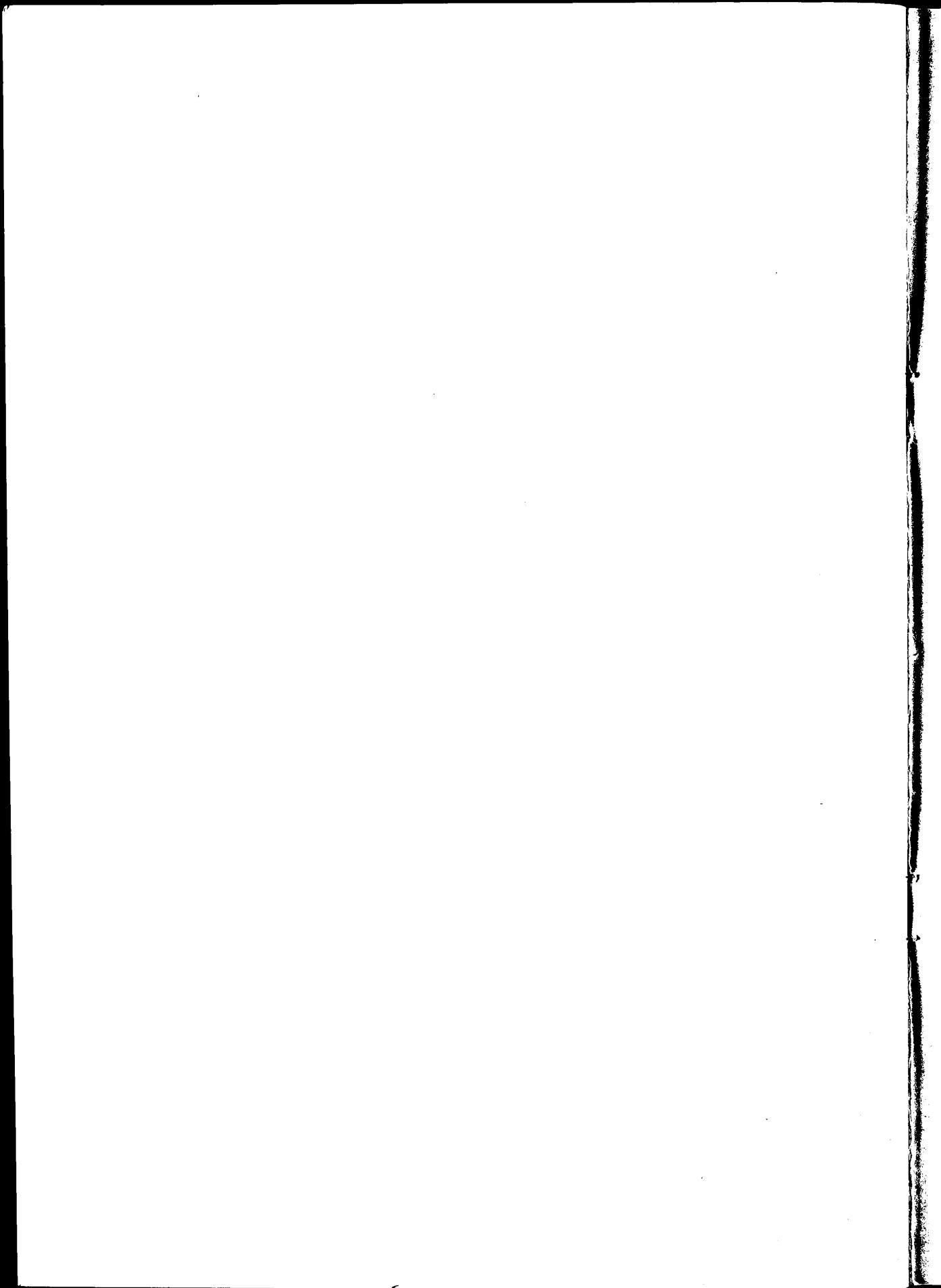
It would be helpful if you could provide us with the names of local contacts who will be available to liaise with our project staff regarding your application. We would appreciate the following information:

(a) Name, job title, and position in the organisation of the person with lead responsibility for carers services in your agency. If this responsibility is not held by an individual, please describe what alternative arrangements apply.

(b) Name and contact details of the person, if different from (a), who will be available to liaise with Carers Impact project staff as regards the processing and follow-up of this application.

*Please send your information to:*

**Michael Powell**  
**Project Manager**  
**Carers Impact**  
**The King's Fund Centre**  
**126 Albert Street**  
**London**  
**NW1 7NF**



King's Fund



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 Launched in October 1992, Carers Impact is a 3-year development project, working alongside health and local authorities to stimulate initiatives that will provide greater practical support for carers looking after elderly, ill or disabled people who cannot manage at home without help. The goal is to make effective carer support a core feature of mainstream community care services.

This first report on work in progress describes the Carers Impact project and what it has achieved during the initial 12 months of its programme. Its prime purpose, however, is to identify key issues affecting the development of better support for carers which have emerged from early work with community care agencies in the field. These include:

- ◆ establishing a 'win-win' relationship with carers
- ◆ carer involvement in service development and provision
- ◆ building commitment to carers within community care agencies
- ◆ working across agencies
- ◆ achieving a balanced strategic approach to service development for carers.

Ensuring that service providers make practical support for carers a priority is a key objective of community care. This report contains valuable information for local and health authorities, voluntary organisations and provider agencies that are interested in making this happen.

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