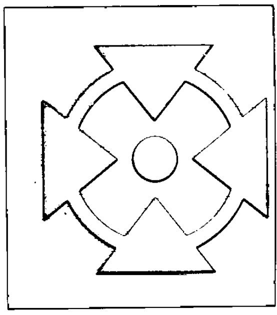
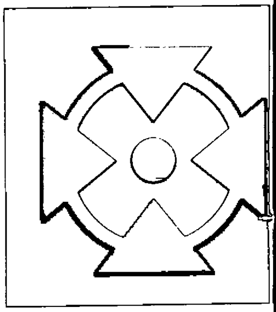
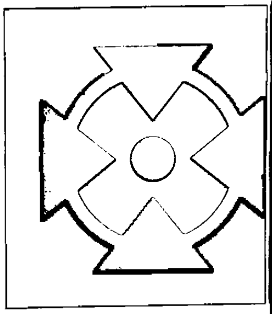
A practical guide to planning and delivering community care services

Janice Robinson
and Lydia Yee







FOCUS
ON CARERS

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Janice Robinson and Lydia Yee

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their 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 and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

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CONTENTS

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FOREWORD

Other Ministers and I take every opportunity to recognise and praise the work and devotion of carers, but they need and deserve more than our praise. It is for this reason that I am delighted to preface this guidance, serving as it does as a practical tool to enable health and local authorities to give carers the support they need.

We are all aware that most community care is provided not by the statutory authorities but by the very large number of dedicated men and women who look after relatives and friends who are disabled, frail or infirm. For these carers to continue to care, they need the help and support of the statutory authorities.

Focus on Carers will help authorities to make some very significant changes in both service provision and professional practice for the benefit of carers. It should also serve to spread good practice by illustrating what different agencies are already doing to build carers' needs and wishes into their planning and assessment processes.

The complementary checklists are designed to empower carers and carers' groups by setting out questions which they can ask their authorities in order to find out what is happening in their area and what is going to happen. They can also help carers' groups to play a full role in the development of services.

This initiative does not stand alone in the development of services for carers. The good news is that impressive initiatives are happening again and again both nationally and locally, in the statutory and voluntary sectors. We are making a reality of the Government's commitment to raise the profile of carers and to ensure that service providers make practical support for carers a high priority.

The picture is encouraging, but there is still much to be done. As we forge ahead with our ambitious programme of change, we must not forget the needs of carers. *Focus on Carers* will help place those needs centre-stage. I warmly commend it to you.

Baroness Hooper

CHAPTER ONE: INTRODUCTION

Addressing the needs of carers – a model way of working?

During the late 1980s it became clear that the needs of carers were finally to be given increased priority by agencies responsible for community care. Following some intensive lobbying, the Government published its White Paper, *Caring for People*, and the following year passed the NHS and Community Care Act. However, the policy initiatives outlined in the White Paper and enshrined in the legislation, welcome as they were, did not address the issues in any detail. It remained unclear precisely how health and social care agencies would be expected to plan better support for carers, assess their needs, and deliver more carer-sensitive services.

There was a need for practical guidance which could help agencies introduce the necessary changes, particularly when it was announced that full implementation of the NHS and Community Care Act (1990) would be delayed. Determined that the needs of carers should remain firmly on the agenda, the King's Fund Centre Carers Unit seized the opportunity to highlight the concerns of carers, to ensure that they were at the forefront in the new planning processes, and to help agencies develop new ways of thinking about, and working with, carers.

Aware of the pitfalls of producing guidance on services without the participation of important stakeholders in community care, we convened a Focus Group to help us identify the key issues for carers and to suggest some practical responses to recommend to community-care agencies. The Focus Group included both carers and service users, as well as managers and front-line staff from local authorities, health authorities and voluntary organisations.

The Group met regularly over six months. The dialogue was always friendly and co-operative, but in common with many local task forces or working groups formed to produce community care plans, we were unsure where to start, which issues should have priority and how we were to ensure that everyone with a stake in community care had the chance to put their views forward.

We frequently found ourselves struggling to reconcile very different perspectives and perceived priorities. As we grappled with the realities and preoccupations of service providers, working in a climate of considerable doubt and uncertainty about future availability of resources, we often found ourselves in danger of losing sight of the sort of world that carers and service users were saying they would like to see. It was these carers and users who kept us on course. Without their involvement from the start we would undoubtedly have produced a very different document.

The Carers' Unit also held a series of one-off consultations with groups of carers, service users and service providers in different parts of the country. These events, which were held during the early stages of our work, gave us a chance to check out the extent which the issues identified by the Focus Group were more widely shared.

We recommend this working process to local agencies as they draw up their 1992 community care plans and start to develop their assessment and care management systems. Having a small working group involving carers, users and committed individuals from different agencies is a valuable way of constructing a local agenda for carers. It can supplement the authority's general consultation programme. We also recommend the practice of checking out ideas with smaller meetings of users, carers, and professionals. There is no doubt, this process demands considerable time and effort on the part of all concerned, but in our experience it helps to build a real partnership which is at the heart of participation. It also results in real ownership of plans by people who have a major interest in converting a shared vision into actual services on the ground.

Why Focus on Carers?

Focus on Carers looks at community care planning, and assessment and care management from the carer's point of view – a focus which is in no way intended to deny the interest and concern which elderly and disabled people have in the new community care arrangements. On the contrary, we recognise that people with disabilities – young and old, and whatever the nature and severity of their disability – are, and should be, the focus of efforts being made to improve community care services.

However, it is now widely recognised that families and friends play a large part in providing care for elderly and disabled people. As carers, they must be considered as individuals in their own right with their own particular needs and preferences. Recent years have seen mounting concern about the plight of carers, as the difficulties and disadvantages they commonly experience have begun to come to light. Many would agree that carers have had a raw deal and although there has been a lot of talk about supporting them, we are still a long way from achieving comprehensive and appropriate support systems.

New opportunities

Carers feature prominently in the Government's policy framework for community care in the next decade. A key policy objective is 'to ensure that service providers make practical support for carers a high priority' (*Caring for People*, para 1.11), in recognition of the fact that 'the great bulk of community care is provided by family, friends and neighbours' (para 1.9).

For the first time, local and health authorities are required to prepare and publish plans for community care services which must show in some detail what services – within available resources – will be provided to those in need. This requirement to produce plans presents authorities with a challenge – to think through in concrete terms what they will do to make support for carers a reality. Vague statements will no longer do. Local authority plans will be monitored by the Social Services Inspectorate (SSI), and health authorities' by Regional Health Authorities. The SSI will also scrutinise the new arrangements for assessment and care management.

The Government's recognition of the key role of carers comes at a time when many local and health authorities have already accepted that carers need support and have begun to develop ways of offering that support. In this respect, Government policy-makers are pushing at an open door – the Government acknowledges that its policy is based on 'the best of good practice which already exists'. Certainly there are an increasing number of examples of support services specifically aimed at carers. The challenge now is to build on these initiatives and learn from their experiences.

Support for carers – hidden agendas?

When authorities talk about improving their support for carers, they are likely to encounter fears and suspicion from carers and service users, worried that support for carers will simply be a way of perpetuating the view that carers are a 'free' resource. Carers may fear that focusing on them will increase the pressure on families, leaving them and the people they care for with little choice as to who provides that care. Changes of this nature may also be seen as a way of deflecting attention away from the real problem facing carers and users – notably the shortage of high quality services for disabled and elderly people. If elderly people and those with disabilities received more, and better quality, community care services, their dependence on family and friends for day-to-day care would be greatly reduced.

These fears and concerns have to be acknowledged. For too long, carers have been portrayed as useful labour, to be tapped as demands for care increase and resources fail to keep pace. Increasing demands for community care services, coupled with their limited capacity to expand their own services, has led many authorities to see that it is in their own interests to provide better support for carers. Whether this is a cynical or a realistic interpretation, the main thrust of Government policy is being seen in some quarters as encouraging more people to take on the caring role and, with minimal support, to continue caring for longer. This is difficult to reconcile with other Government statements promoting independent living and choice for service users. Finally, delays in implementing the new legislation has only served to increase doubts about the Government's avowed commitment to community care.

There is also real anxiety on the part of service users who, having campaigned for years to secure services which would enable them to live independently, now fear that carers and carers' needs will take precedence over their own needs and wishes – that user-centred will become carer-centred.

Local and health authorities will confront these varying concerns as they develop new arrangements for community care. They will be forced – as we have – to consider their response to what a growing number of carers and users are saying loudly and clearly.

Reconciling carers' and users' interests: striking a balance?

We have chosen to focus on carers because we believe they have been shamefully neglected in the past. Service providers can no longer concentrate their efforts on meeting the needs of people who have no family or friends willing or able to care for them. Millions of people provide help to disabled relatives who accept and may, indeed, expect this help. However, it is unreasonable to expect that the support provided by carers should be seen as a total substitute for other services. The two support systems need to work together and complement one another.

A balance must be struck between the needs of elderly and disabled people and those of carers. Both have many interests in common but their experiences will be different and so, at times, will their needs. (A carer may want a break from caring, say, but the person they are caring for may not want to use the available respite care services.) Conflicting needs and wishes can arise and these need to be made explicit, acknowledged and resolved through compromises acceptable to both parties. At the end of the day, carers and users must be seen as individuals who both have needs and rights which must be recognised in the provision of community care.

The contents

The two main chapters – Chapter 2 on community care planning, and Chapter 3 on assessment and care management – highlight key issues for carers and suggest what needs to be done to address those issues in practical terms. Chapter 4 looks at how momentum in implementing new plans and procedures can be maintained. A series of examples describing practical initiatives already taking place in local areas is laid out on pages 79-104. In each case, a brief description of these developments is given, together with contact names where further information can be obtained.

Using this publication

Focus on Carers is intended primarily for local and health authorities; it will be especially useful to officers responsible for developing community care plans and for setting up and implementing the new assessment and care management systems. Voluntary organisations and carer or user groups may also find the guidance a useful aid to their work with statutory agencies.

Our aim has been to provide broad practical guidance to all those involved in developing support for carers. It does not set out to offer detailed step-by-step advice nor can it claim to be a comprehensive compendium of everything that should be done to support carers. It is a short guide which aims to provide vital reference points.

There are numerous sources of more detailed information and advice and we include a list of further reading as an appendix to this manual.

You may already be working in many of the ways we suggest and space is provided for you to note where progress has already been made and what further action can be taken.

Two checklists have been appended. These have been published together as a single leaflet and distributed to carers' groups throughout the country. They are reproduced here so that agencies can see the sorts of questions carers are being encouraged to ask in order to find out what practical support they may hope to receive in the future. We suggest that you also try to answer the questions to see whether the concerns raised are being met by your authority.

The checklists may be freely reproduced by organisations for use in their work with and for carers.

A word about words ... defining our terms

We have used the term *carer* to describe anyone who regularly helps another person with everyday tasks such as: shopping, cooking, or housework; helping someone with personal tasks such as washing, dressing and using the lavatory; or help with getting around the house or around the neighbourhood when someone has mobility problems. Carers are also involved in providing emotional and social support. A carer may live in the same house or flat as the person they are looking after or they may live separately. They may be providing full-time care or they may be providing care at certain times such as during the evenings and weekends. Someone who has paid employment outside the home may be a carer – not everyone needs round-the-clock care – or they may be sharing the care with others.

Carers can be any age – some are children, caring for a disabled parent, while others may be elderly. More than four out of five carers are related to the person for whom they are caring, the remainder being friends and/or neighbours.

We have used the term *service user* (or sometimes just *user*) to refer to someone who either uses, or could use, the sort of help which carers or service-providing agencies offer. Their needs may arise because of physical or sensory disabilities, learning difficulties, mental health problems, or long-term illness.

It is important to remember that *carers* can be *service users* too. They may need services to support them in their caring role – including counselling, information and advice, and services which give them a break from caring.

An important but neglected group of carers and users are those who have particular needs relating to their racial, cultural, and/or religious backgrounds. While we are aware that the terminology is constantly changing – and is often a matter of individual preference – we have written about *black and minority ethnic* carers and users, aware that the term will be acceptable to some but may not be to others.

CHAPTER TWO: COMMUNITY CARE PLANS

Introduction

By April 1992, local authorities will have had to produce their first community care plans – either jointly, or in close collaboration, with district health authorities. These plans will normally cover a three-year period but will be reviewed and updated annually.

In considering comunity care plans in relation to carers' needs, the Focus Group drew up the following statement which sets out what it believes carers can reasonably expect to see in community care plans:

- A statement showing who is regarded as a carer.
- An awareness of the key role carers play in assisting disabled people living at home.
- Key elements of a policy, showing what the authority is prepared to do to help carers and the people for whom they care.
- Arrangements for consulting carers and users about services, including how people in black and minority ethnic communities will have opportunities to voice their needs and preferences.
- Ways in which information about existing services will be made available to carers and users.
- How carers' needs will be assessed.

- Changes and improvements which will be made in services affecting the lives of carers and users.
- How services will be provided to suit the particular needs and wishes of black and minority ethnic carers and users.
- A system of charging for services which does not deter carers and and users from obtaining the services they need.
- Arrangements for ensuring good quality services.
- Evidence of a commitment to equal opportunities policy and practice.
- Support for advocates who will help carers present their case.
- Financial and other support which will be made available for carers' organisations and self-help groups.
- Evidence that health and social care agencies in the area agree on the future direction of support for carers.
- How carers will know whether plans have been put into action.

Policy

> *A key responsibility of statutory service providers should be to do all they can to assist and support carers.*
> (Caring for People, para 2.3)

From slogans to policy

Carers will want to know what their authority is prepared to do to help them and those for whom they care. Broad policy statements acknowledging that carers provide the bulk of community care and should therefore receive help and support are not enough. Carers have become frustrated with vague commitments to 'care for the carers' which are rightly seen as no more than empty slogans if, as if so often the case, they are not supported by clear statements showing what the authority is actually prepared to do and how it will meet its aims and objectives.

A clear policy with specific aims and objectives will guide the planning process itself so that everyone with a stake in services can judge whether plans and provision for community care are consistent with declared policies.

A lack of clear policy direction has resulted in frequent confusion about the aims of support for carers. It has also resulted in some practical initiatives which have failed to address the real needs of carers and those they care for. For instance, the authority's focus may be on helping to set up carers' groups to provide emotional support, but important as this is, it fails to address the even more pressing need for practical help in the home – a service need which is often ignored.

Understanding carers' needs

Carers will expect policies to be based on an accurate and realistic appraisal of their situation. Authorities need to be well informed about who their local carers are, and to be able to answer these and other questions: How many carers are there? What are their ages? What are the proportions of male and female carers? What type and level of care are they providing? With this information, authorities will be in a better position to decide how they might work with carers to provide the most appropriate help.

It is equally important for authorities to ascertain what the needs and preferences of local carers are and how carers themselves would like these needs met. Do they want home-based respite care, for example, or would they prefer a separate respite care facility? Do carers want a shopping service or would they prefer to have a sitter, who would enable them to get out of the house and shop for themselves? Can services offer people real choices?

Carers by choice?

Policy statements should make it absolutely clear what the authority's beliefs and assumptions are regarding carers as it is these which form the roots from which services will grow. Carers are still too often seen as an unpaid army, marching on its goodwill, whose needs and wishes take second place to those of the people they care for. Carers' expertise should be acknowledged and their entitlement to support spelled out. The extent to which carers will be able to choose whether to care in the first place should be made clear. They should be able to make clear choices about the care they will provide; and the possibility that they will at some point relinquish those caring responsibilities should also be considered.

Defining priorities

Most carers can accept that resources are limited and that agencies must therefore set priorities, but they may find it harder to understand how the agency has selected and defined its priorities. Someone providing round-the-clock care, seven days a week, for someone with severe behavioural problems or double incontinence, may justifiably find it hard to understand why others with apparently fewer responsibilities receive more help.

Particular groups of carers – women, members of black and minority ethnic communities, people caring for relatives with severe mental health difficulties, for instance – may feel that they are seen as a low priority by those who shape policies and plan budgets.

Whether as the result of a conscious policy decision or not, some authorities tend only to offer services to carers when a crisis occurs or when the caring situation is threatening to break down. Others have decided to invest their resources in early intervention to prevent crises occurring or caring situations breaking down. Authorities must be clear about how and when a crisis service will be offered.

Authorities need not only to set out clearly defined policies relating to priorities but these priorities should also be seen as fair and equitable to carers and users.

Action points

- **Develop your authority's thinking about policies relating to carers** through discussions with carers and service users – as well as with members and officers of the authority, particularly those who are in regular contact with carers. Precisely how this is tackled will vary from area to area but asking carers and service users for their views and using these to shape policy is a crucial stage in developing community care policies.
- **Assemble as much background information as possible** about carers and caring to inform your policy-making and planning processes (see Practical Initiatives, Example 3, p. 13). There is a wealth of published research to draw on and further information can be gathered from carers and carers' organisations in the area, as well as from national organisations.
- **Define who you consider to be carers,** at the start of your policy statement. Show clearly that the policy concerns all carers, regardless of their age, sex, race, social class or the type and level of disability of the person they care for.

Cont/d

Progress check

Action points (cont/d)

- **Use the policy statement** to show how carers will be treated by the authority, recognising them as equal partners in service provision and as people with unique experience and skills to offer.
- **Show that your authority recognises carers' entitlement to support** in their own right. Highlight the main forms of help which will be offered to meet carers' own needs, and who will be entitled to this help.
- **Indicate clearly any priorities the authority has established** in relation to meeting carers' needs and the reasons for this so that carers understand the reasons why they may nor may not be entitled to use a particular service.
- **Draw up a written policy statement of beliefs, aims and objectives** relating to carers and include this in your community care plan.
- **Devise and implement a strategy for informing carers** and users about (a) your policy, and (b) your services (see 3.2. below).

Progress check

For examples of carers' policies developed by local and health authorities, see Practical Initiatives, Examples 1 and 2, pp.81-85.

For further information on this issue, see Useful Reading, pp.105-106.

Consultation and participation in the planning process

> *In their plans, social services departments should identify how they intend to consult on plans with ... voluntary organisations representing carers.*
> (Policy Guidance, para 2.25)

A range of ideas, beliefs and practicalities will inevitably come into play as policies and plans are formulated. Carers and service users should have opportunities to participate in the planning process from the start, not when plans have already been decided.

Carers are the experts

If asked, carers and users have a great deal to say about their lives and about the sort of help they need. Being at the receiving end of services, they will have views about the quality of services and changes and improvements which could be made. Too often services continue to be set up and run not in response to what carers and users are saying they need but on the basis of what professionals have decided would be best for them. A service which is really 'needs-led' will be based on what carers and users are saying about their lives and about their experiences.

A better use of resources

Setting up and providing services with no idea of whether carers and users value them is an unwise use of resources. For instance, plans to provide or increase residential facilities for respite care – which are expensive to set up and run – will be misguided, and a waste of money, if carers and users are making it clear that other forms of respite care are more acceptable (e.g. respite in the person's own home or with a 'foster' family).

Creating a dialogue

In the past, carers and users were rarely asked for their views; services were provided on a 'take it or leave it' basis, with the result that both carers and users felt powerless. This is slowly changing as authorities have begun to take consultation more seriously, building up trust and attempting to hold a proper dialogue with the people for whom they provide services. Carers and users generally speak warmly of these efforts to find out what they think. They can see that perhaps they finally have a chance to influence events. Increasingly, carers' groups are coming to expect consultation to take place – and there is anger and dismay if it does not.

When properly conducted, consultations can empower carers and users as they become more informed, can speak out, and can have a real say in decisions which affect them. In recent years some important lessons have been learned about consultation:

- Carers do not like being asked to comment on plans which have been drawn up before their views have been taken into consideration.
- 'Going through the motions' of consultation – when it is clear that no real changes will be made in the light of any feedback from carers and users is a waste of time, and frustrating and offensive to carers and users.
- When staff use professional or 'service' jargon, carers and users may complain – or, worse still, remain silent. Everyone needs to be able to understand what is being said in order to participate in discussions.
- Consultations held in places unfamiliar to carers and users and conducted in a very formal manner will not encourage real participation. Authorities will get better feedback if they do everything to ensure that participants feel comfortable.

- Consultation events which are held at times which do not suit the circumstances of carers will not be popular.
- Few carers or users want to discuss detailed operational matters such as a change of structure in the agency or detailed operational policies – the sort of issues which tend to fascinate staff.
- Carers and users have plenty to say about their own experiences, needs and wishes and they find it perplexing to be told that these are 'irrelevant' or 'unrepresentative'.
- Carers and users can have different experiences and views. It is important to consult both, while recognising that sometimes (e.g. users who are severely confused or who have profound learning difficulties) this will not be possible.

Action points	**Progress check**
☛ **Seek the views of carers' organisations,** user groups and organisations representing black and minority ethnic carers and users at an early stage in planning your authority's consultation activities. They will usually have plenty of ideas about the best ways of proceeding, and are likely to be able to help you find the right people to consult. If you do this at the start, a partnership is more likely to develop which is based on trust and co-operation and which taps the knowledge and expertise of carers as fully as possible. Cont/d	

Action points (cont/d)

Progress check

- **Design a programme of consultations** which is built into the ongoing work of the agency. This might include: surveying the needs and preferences of carers and users through a postal questionnaire or face-to-face interviews; public meetings; less formal discussions with small groups; and participation of carers and users in working parties and committees. A mixture of approaches is essential so that as many people as possible can have their say. Not everyone will want to, or indeed be able to, attend public meetings, for instance, so being able to offer people choice is important.
- **Publicise consultations as widely as possible**. Notify staff who are in regular contact with carers and users: home care staff, district nurses, etc.; send information to local community groups; distribute posters and leaflets in GPs' surgeries, out-patient clinics, chemists, libraries and other public places; use the local press and radio.
- **Involve senior managers in consultation meetings**, etc. Unlike hands-on staff, they may not be in close touch with carers and users, and therefore may be less aware of their experiences.
- **Allocate resources to consultation work**. Staff will be needed to identify local carers and users, to organise events and activities and to help make it as easy as possible for carers and users to participate. Money will be needed for carers' and users' travel expenses and some carers will need substitute care in order to attend meetings. Interpreters may be needed for people whose first language is not English and signers for people with hearing difficulties.

Cont/d

Action points (cont/d)

Progress check

- **Use meeting places which are convenient for carers and users,** and venues with which they may already be familiar. This is particularly important for carers in black and minority ethnic communities.
- **Be prepared to follow up problems** which individual carers and users may raise during consultations. This may entail referral to staff in relevant service-providing agencies.
- **Feed back to carers and users** what will happen as a result of the consultations, and keep them in touch with further developments. Agree clear procedures for doing this – for instance through communication with the local carers' group, if that is appropriate.
- **Ensure that community care plans show the extent to which consultations with carers and users have influenced your planning.** Indicate how consultation will continue and develop, and how you intend to reach out to those with whom you have had little or no contact as yet – for instance, those who are not receiving any services, or who are known to have a low take-up of services such as black and minority ethnic carers and users.

For examples of consultations with carers, see Practical Initiatives, Examples 4 and 5, pp.87-89.

For further information on this issue, see Useful Reading, p.109.

Information about services

> *In their plans, social services departments should identify ... what arrangements they intend to make to inform ... carers about services.*
> (*Policy Guidance*, para 2.25)

The need for information

Many carers, particularly those who are elderly, have little or no idea about what existing community care services are available. Most will know about hospital or residential care, but relatively few will know about the community services which have been developed in recent years to support people in their own homes.

However, even when carers go looking for help, they frequently complain of the time and effort involved in finding out what is available and how they can gain access to it. Sometimes they only find out when it is too late – when the person they cared for has either died or moved into residential care. Lengthy delays between asking for information and the worker getting back in touch with them – or, sometimes, never getting back in touch – are also a source of anger and frustration. It can often seem as though information is being witheld by 'the people who know', perhaps afraid that there will be too many requests for help? In some cases, workers who are in close touch with carers and service users know about their own service but not about other sources of help; carers can find themselves passed from pillar to post in their quest for information. Little wonder that the search for help is commonly portrayed as a frustrating struggle through the 'welfare maze'.

Providing the right information

Despite the considerable increase in the availability of information, it can still fail to meet carers' needs. Guides and leaflets may omit essential facts such as opening hours, contact addresses and telephone numbers, charges for services and eligibility criteria. Sometimes the information is out of date almost as soon as it is produced. Some directories may be inappropriately organised with services grouped by agency rather than area of need. The use of professional jargon or bureaucratic language can also be offputting. Access to information about services is also severely restricted for people who do not speak English or who have a communication difficulty, unless their particular needs have been addressed – for example, through providing information material in non-English languages or in Braille or on tape.

Getting the information to carers

At the end of the day, though, however much information has been written down, if those producing it have not really thought about distribution, resources are simply being wasted. The result is offices piled high with boxes of leaflets, posters and books which have failed to reach the very people for whom they are intended.

We know that some carers would welcome what is known as a 'service brokerage' service – an independent organisation which employs a 'service broker' who brings together comprehensive information about services and helps a user and their carer(s) to make informed choices based on the options and resources known to be available. One of the main advantages of service brokerage is that it operates separately from service providers, and service brokers should therefore be able to give more independent and imaginative advice to users and carers.

Action points

- **Consult carers and service users** about their information needs.
- **Pilot all information materials with carers** before they are published to ensure that content and presentation will meet their needs.
- **Draw up an information strategy**, showing the types of information to be made available (e.g. leaflets, posters, videos) and how and where it will be disseminated.
- **Develop a 'one-stop' facility** – a central information point where carers and users can obtain information on a wide range of services and be referred to agencies holding specialist information.
- **Produce a series of posters, leaflets and general guides** which encourage carers to seek out services they need; update the information on a regular basis.
- **Consider how you can maximise limited resources** by adapting national information materials – for instance, a booklet on respite care services. Savings in developing these materials can be used to produce inserts on what is available locally.

Cont/d

Progress check

Action points (cont/d)

- **Take information to the carers** rather than expecting them to come to you: use local radio and newspapers, make household drops, put information in places where carers are likely to see it such as GP surgeries, chemists, supermarket noticeboards, and local libraries.
- **Set up regular information days, courses and workshops** for carers. These could cover a range of issues, e.g. welfare benefits, lifting techniques, and the provision of information on specific types of disability or particular local services.
- **Ensure that information and advice workers** both within the authority and in other agencies have relevant and up-to-date information about services.
- **Set targets for a speedy response** to requests for information and monitor to ascertain whether these targets are being met.
- **Train front-line staff** (e.g. receptionists, community nurses and home helps) to be able to provide appropriate initial information to enquirers.
- **Summarise in your community care plans how your agency proposes to provide information about services to the public** and how you plan to target particular groups such as carers.

Progress check

For an example of a local information strategy, see Practical Initiatives, Example 6, p.90.

For published guides for carers, see Useful Reading, p.107.

Assessment of carers' needs

> *Carers who feel they need community care services in their own right can ask for a separate assessment.*
> (Policy Guidance, para 3.29)

Assessment is the key which opens the door to services for elderly and disabled people and their carers, but it is only very recently that carers have been entitled to have their needs assessed at all. Their willingness and ability to care have simply been taken for granted.

Recognising the carer's right to choice

People may not necessarily make a positive choice to become a carer. It may happen gradually – when an elderly relative becomes increasingly frail, for instance. Or it may happen suddenly, following a serious accident or the onset of an illness. At the same time, health and social care professionals involved with the situation may assume that relatives will – or should – take on this role. As a result, they will avoid discussing the needs and wishes of potential carers or whether the person needing care might prefer other arrangements to be made. Women may experience particular pressure in this respect, caring still being seen as a predominantly female role. In the case of black and minority ethnic communities, professionals may assume that extended family networks will always provide any care that is needed. As a result, an elderly or disabled person needing care may receive reduced levels of care – or no services at all – if relatives are deemed able to 'cope'.

It is no wonder that carers often complain of being invisible. After all, no one asks them how they are feeling or what they want or need. When staff are holding discussions with the carer and service user, it can be hard for the carer to speak freely – perhaps to express their resentment at having to care – for fear of offending or hurting the feelings of the other party. At times, the views and preferences of carers and service users may differ or may even conflict with each other. In fact, the presence of a third party – an 'outsider' to the situation – who can listen to the views of both parties, may enable carer and user to negotiate solutions which respect the needs and wishes of both parties.

All authorities are in the process of reconsidering their procedures for assessment as they draw up their community care plans for 1992, and Chapter 3 looks at assessment issues in more detail.

Advocates

Building confidence

Many carers and service users can speak for themselves, particularly when staff in services make it clear that they are there to listen and encourage them to talk freely. Others, though, feel less confident in dealing with 'officialdom' or with professionals. However confident they may feel, though, most carers have little time and energy to argue their need for help – often time and again – to the many different professionals responsible for service provision.

Some carers and service users would welcome someone to provide moral support, and, where necessary, speak on their behalf, to help present their views and press for the services they require. A person coping with the impact of a disability or illness in the family can experience a range of difficult and conflicting emotions, with the result that hasty decisions are taken without the implications being fully understood by either the service user or the carer. In the confusion, both parties can feel that they have not had a proper chance to say what they would really like to happen. When approaching agencies for help, many will also feel unsure and vulnerable, maybe as the result of previous bad experiences when they asked for help. In these circumstances, it can be useful to have a trusted friend to act as an informal advocate and support. Alternatively a carer might want a more formal arrangement with an organisation which provides volunteer advocates.

Having someone who is 'on your side' can be helpful when needs are being assessed and decisions made about future service provision, particularly when that person has no stake in service-providing agencies or departments and is totally independent and unbiased. The advocate needs to be independent and separate from any service-providing agency so that he or she can truly represent the carer's and user's interests rather than those of the agency.

Advocacy can also be useful when carers' and users' needs conflict. While there is a danger of overestimating the incidence of conflict, there are undoubtedly occasions when separate advocacy, one acting on behalf of the carers and one on behalf of the service user, is necessary.

Apart from enabling people to speak on behalf of individual carers and service users, community care agencies also need to work actively with organisations who represent their interests. These may be representatives of carers' and service users' groups who will themselves be carers or users; but they may also be workers from voluntary agencies and community groups who are closely involved with carers and/or service users. These 'advocates' can play an important role in policy and service development – by taking part in working groups or committees dealing with community care issues, for instance.

Action points

- **Ensure that carers and users have access to independent representatives** if they wish to and that they know where they can find such representatives.
- **Make it clear** (e.g. in information material) **that a friend or other support-person will be welcomed** when carers are meeting with professionals and other service providers.
- **Support the training and employment of independent advocates** by offering financial and practical support to groups wishing to recruit and train advocates.
- **Ensure that organisations representing the interests of carers and users are involved in committees** and working groups responsible for planning and delivering community care services.

Progress check

For examples of advocacy services, see Practical Initiatives, Examples 11 and 12, pp.98-99.

Services

> *The Government believes that the key components of community care should (include) services that respond flexibly and sensitively to the needs of individuals and carers.*
> (*Caring for People*, para 1.10)

Carers want the very best health and social care services for the people for whom they care, but they also have a legitimate interest in those services which provide them, as carers, with emotional support, and which relieve them from continuous caring responsibilities.

Emotional support

Caring is frequently stressful and can leave carers feeling anxious, angry or guilty. They need the chance to express these feelings to others and to understand they are typical reactions to their situation. Counselling, self-help groups, and telephone helplines are all potential sources of emotional support. Having someone to talk to who understands what they are going through and who does not make moral judgements can make all the difference between whether or not a carer is able to continue looking after someone.

Much of the emotional distress experienced by carers relates to the unrelenting, often stressful business of caring unsupported over long periods of time; if the sources of stress are not – at least partially – alleviated by the provision of both practical and emotional support, the carer's distress may remain unabated.

Shared Care

Most carers want to care but they usually also want to share that responsibility with others. Many will want assistance with practical tasks in the home (housework, shopping, gardening, etc.) and with personal care tasks (bathing, dressing, eating, toiletting, etc). Like anyone else, carers also need time to themselves, to relax, to do the things they want to do, knowing that their relative or friend is well cared for in their absence. They will want to be satisfied that services offered are appropriate for both the user and the carer.

Alternatives to family care

An alternative arrangement sometimes needs to be found which suits both the carer and the person for whom they are caring. People with disabilities (particularly younger people) have a right to independent living arrangements where they do not have to rely on either family or friends. There are also occasions where the carer is unable to carry on (perhaps due to their own ill-health or increasing infirmity), or both parties may wish to end the caring relationship and suitable alternatives have to be found. Services which enable these choices to be made in the best interests of all concerned should be at the heart of good community care provision.

Allocation

Every area in the country has a range of services – delivered either to the person's own home or elsewhere – which can assist both carers and users. But where an elderly or disabled person is being looked after by a relative or friend, they may be seen as a low priority, particularly when resources are limited. Priority has traditionally been given to people without carers – a particular problem in home care and community health services – the assumption being that carers can be left to cope.

Mainstream change

New initiatives, which recognise the carer's own need for support and relief, are emerging. However, these have been largely confined to small-scale specialist schemes or demonstration projects – often situated within the voluntary sector; wider changes in policy and practice are much less evident in statutory health and social care agencies. Carers' concerns are still largely marginalised by the very agencies that are best resourced and which should be best able to assist them. So it is not surprising that local and health authorities are altering current provision with little consideration of their possible impact on carers. The introduction of charges for services that were previously provided at no cost, or hospitals sending people home earlier, are just two examples of the sort of changes which can affect dramatically the lives of carers.

Quality

Both carers and users frequently express concern about the way services are offered and delivered. For instance, carers will be reluctant to use relief care if the service user ends up unhappy, bored or demeaned by the experience.

Inflexible services are another bone of contention. Too many services only operate within 'office hours' or are delivered at the provider's convenience. Most people do not want to go to bed at 7 p.m. – especially if they are not going to be able to get up until 10 a.m the next morning, and a special transport scheme which has to be booked two weeks ahead is not much use to someone invited out on the spur of the moment.

Action points

- **Carry out an area-wide service audit** to assess how useful or not carers and users find current services. Involve carers and users in this process (see pp.15-20) and encourage managers and front-line staff to assess services critically in order to identify necessary changes in the way their service is delivered.
- **Identify areas where improvements can be made** in both the short and the longer term. Specify what changes are to be made, who is to be responsible for implementing them, and the deadlines for their implementation.
- **Develop a record-keeping system** showing the receipt of services by individual carers (and by users with carers). Monitor service allocations to carer households.
- **Produce clear written guidance** on carers' entitlements to services for use by all staff responsible for allocating services.
- **Organise training and staff development programmes** for all service providers to increase their awareness of carers' needs and enhance their skills when working with them. Use carers as a training resource as this will enhance the understanding and learning of staff.

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Progress check

Action points (cont/d)

- **Develop quality assurance standards for all services,** which build in carers' and users' perspectives. Monitoring and evaluation of service performance should focus on the experiences and perceptions of those who use services in order to determine the quality of services.
- **Maximise the flexibility of services** by delegating decision – making and devolving responsibility for budgets wherever possible. This should mean that decisions about how funds are allocated are based on a more accurate perception of the needs and wishes of carers and service users.
- **Encourage service users and carers to decide what services they wish to be purchased** and from whom as a means of increasing individual choice as to how needs are met.
- **Ring-fence a proportion of relevant service budgets** to ensure that a quota of services go to users who are being supported by friends and relatives. This should be an interim measure until additional resources are forthcoming to enable the expansion of those services currently targetted solely – or mainly – on those living alone or those without carers.
- **Where alterations to current services are being proposed, consider the implications for carers and users** and highlight these in all committee reports which deal with these changes.

Progress check

For examples, see Practical Initiatives, Examples 13 and 14, pp.100-103.

Also see Useful Reading, Service Development, pp.108-109.

Charges for services

> *The provision of services ... should not be related to the ability of the user or their families to meet the costs.*
> (Policy Guidance, para 3.31)

Charging anomalies

Carers and users soon discover that whether or not you pay for a service can depend on who provides the service, an anomalous situation from their point of view. For instance, they quite rightly find it inexplicable that respite care provided by the health service is free, but charges may be levied when it is provided by local authorities. Why, they frequently ask, are Crossroads care attendants almost invariably free, while a charge is made for home care services provided by the local authority? Many will not be aware of the extent to which the rules regarding residential care are determined by central government while charging policies for local authority home care and day care are the responsibility of its social services committee.

Fair charges

Not all carers and users either expect or want all services to be free – indeed, some feel quite strongly that they retain more dignity and control if they pay. However, they may also feel that while some charges are fair and reasonable, others are not and some people, at least, should be exempted from payment. Carers who are paying a flat-rate token charge for a service may rightly question whether the time and effort involved in collecting charges actually costs more than the money raised.

Many carers and users are on low incomes, struggling with the extra costs associated with disability or illness and with no hope of increasing their incomes through paid work. Many, though, are ignorant of the welfare benefits to which they are entitled or have real difficulties in claiming them. Some benefits – mobility or attendance allowance, for instance – which are intended to buy in specific services, end up going towards meeting general household expenses or the level of benefit is too low to meet the real cost of buying in the help for which it was intended.

Charging carers for services

For households on welfare benefits, or otherwise on low incomes, it can come as a considerable shock to discover that services which were hitherto free or available at minimal cost are now to cost considerably more. Carers, in particular, are being placed under great pressure to top up payments for services where their relatives do not have the means to pay the full amount themselves. Although this problem is particularly acute in the case of residential care fees, it is not unknown in other community care services.

The process of financial assessment can be humiliating, reminiscent of Poor Law days; carers can feel outraged when, having asked for help for their relative, the response is an investigation into their own resources, apparently to be drawn on for the care of their relatives. This is particularly galling when a carer's sole source of independent income is Invalid Care Allowance.

Action points

- **Establish clear policies** on which detailed charging arrangements are made.
- **Indicate clearly in all written information about services whether or not the service is free.** Where a charge will be made, outline the current charges levied for particular services, and show who is exempt from payment and why.
- **Seek the views of carers and service users on what they regard as fair and reasonable in terms of charges**, tapered scales and exemptions, where there is local discretion on whether a charge is made for services.
- **Review the impact of charging policies** on the take-up of services and on the lifestyle of carers and users receiving services for which payment is made.
- **Consider whether charges for services are cost-effective** in terms of the administrative costs involved and the likely revenue from charges. Remember, too, that charges may deter some people from using services and the implications of this also need to be assessed. For instance, if someone is not using a respite care service because they cannot afford to meet the cost involved, does this mean they are more likely to request permanent residential care?
- **Instigate or support welfare benefits take-up campaigns** focusing on the entitlements of service users and their carers.

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Progress check

Action points (cont/d)	Progress check
☛ **Develop procedures for checking that individuals are claiming all relevant benefits.** With appropriate training, this can be done by all health and social care staff in contact with carers and users. Special advice sessions can also be arranged at places used by carers and users, e.g. clinics, day centres.	

For further information on this issue, see Useful Reading, Policy and Research section, p.105.

Backing for carers' organisations

There are many kinds of carers' organisations with differing structures and functions. Most are relatively new on the scene, and the growth of carers' self-help and support groups, voluntary organisations and carers' forums looks set to continue through the 1990s. Carers themselves have been instrumental in setting up and running many of these organisations but substantial backing is required to ensure their sustained growth and development.

The value of carers' groups

It is evident that carers value these groups and organisations which enable them to share their feelings and experiences in a safe environment. They value the time away from caring and the conversations and activities which can mean a great deal to people whose lives are so often isolated and restricted. Carers' groups are also an important forum for exchanging information; it is not unusual for carers to report that it was only through talking to other people in the group that they learned about a particular service or welfare benefit. Other groups have benefited from inviting professionals to share their skills and knowledge, on topics such as safe lifting, stress management, and assertiveness training. For many carers, groups are also an effective means of combining forces to campaign for more and better support services. This is particularly true in the case of carers' forums where there are clear avenues for putting across carers' views to authorities responsible for service provision.

Support for carers' organisations

Voluntary organisations can offer a range of help including: provision of information and advice; acting as advocates for individual carers and pressure groups by speaking up for members' interests; practical assistance in the home, day care, and social opportunities.

These groups and organisations need backing, though, if they are to be effective. Support is needed in both cash and kind. Equally important, their independence and their right to a say in the way community care is organised need to be recognised by statutory service providers. Any backing given to groups and organisations should not be at the cost of muzzling constructive criticism put forward by carers or staff employed by these groups.

When working with carers' organisations, authorities need to remember that although carers may want to have a say in how services are planned and delivered, their time and energy is not unlimited. Caring is often tiring and time-consuming and they will need support to make an input to consultation exercises as well.

Action points

- **Designate staff within the authority** and/or fund voluntary sector staff to assist in the setting up and running of carers' groups and forums. Make it clear at the outset whether this assistance is short-term 'seed money', to enable carers ultimately to run and resource their own activities. It is unlikely that a carers' organisation would be able to fund its own workers and the authority may feel that providing long-term support workers for carers' groups is a tangible demonstration of their commitment to consultation in community care.
- **Support the activities of carers' groups**; make premises available for meetings; assist with transport; and provide substitute carers (or payment for care) to enable relatives to attend carers' group meetings.

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Progress check

Action points (cont/d)	**Progress check**
☛ **Ensure that any grants made to carers' groups offer them sufficient security** so that they can retain experienced staff and build in consistency and continuity into their activities. Organisations which lurch from one financial crisis to the next are inevitably less effective. ☛ **Invite carers' groups and organisations to nominate representatives to your authority's working groups** and committees responsible for the development of community care services. ☛ **Maintain a central register of organisations**, describing what they offer and to which particular groups, etc. Ensure that this is regularly update and widely disseminated to carers.	

For examples, see Practical Initiatives, Examples 5, 11 and 15, pp.98-104.

For further reading on this issue, see Useful Reading, Service Development section, pp.108-109.

Fair treatment

> *Good community care will take account of the circumstances of minority communities and will be planned in consultation with them.*
> (*Caring for People*, para 2.9)

Some groups of carers and users are receiving a particularly raw deal. They experience multiple disadvantage as services fail to take account of their specific needs or operate in ways which discriminate against them, blocking their access to the services they require.

Do women carers get less help?

Female carers may find it more difficult to obtain services than male carers. Those allocating services may operate from the premise that men are less able to cope than women. Service providers may also assume that while it is more important for men to remain in paid employment outside the home, women can more easily give up their jobs and become full-time carers. Service packages offered to women may not meet their requirements and preferences. If housework is seen as 'women's work', for example, then only male carers may be offered home care services.

Carers are all ages

Very young or older people are often treated unfairly, being expected to take on caring responsibilities which would never be tolerated within formal care services. Children and teenagers may be denied the normal opportunities enjoyed by others of their age when they become carers – often because of a parent's disability or serious illness. At the other end of the spectrum, service providers may assume that an elderly carer will be willing and able to carry out heavy tasks even when their own health and strength may be failing.

Black and minority ethnic carers need help

Carers in black and minority ethnic communities feel that their needs are virtually ignored. It is only comparatively recently that service-providing agencies have begun to consider them as potential service users by, for instance, producing publicity materials in languages other than English. Mistaken beliefs that in these communities people are uniquely equipped to care for one another in extended family networks have resulted in considerable neglect. Low take-up of services may also be the result of previous experiences (or expectations) of racist attitudes and behaviour among staff in service agencies. The kinds of services on offer may not be acceptable: staff may be unable to communicate with users whose first language is not English; users may have no chance to associate with others of the same racial or ethnic group; and the way services are run may not conform to carers' or users' religious or cultural customs.

Gay and lesbian carers

Gay men and lesbian women caring for their partners are prone to double disadvantage. Authorities may not even be aware of gay and lesbian carers in their area and so may not see them as part of the carers' population. Not being recognised as 'next of kin' can deny them recognition as carers with support needs of their own. They may also experience discriminatory attitudes on the part of staff involved in assessing need, and allocating and delivering services, particularly – but by no means exclusively – where illness and disability is associated with AIDS and HIV.

Action points

- **Audit the take-up and use of services** by those groups who are known to be vulnerable to unfair, discriminatory treatment.
- **Consult under-represented groups** about their needs and experiences of services (see pp.15-20) and how they feel services could best meet their particular needs.
- **Set up development programmes** to improve support for carers in disadvantaged groups, and locate responsibility for programme design and implementation at senior management level.
- **Set performance targets for particular service areas.** Develop mechanisms for annual reviews of progress towards meeting these targets.
- **Indicate in service specificiations what providers are expected to do** in terms of meeting the needs of particularly disadvantaged groups – e.g. targetting publicity about their service to those groups; monitoring take-up; setting quotas, organising staff training to increase competencies in working with particular groups.
- **Grant-aid community groups and voluntary organisations assisting disadvantaged groups** of carers and users. Groups could, for example, indicate: the number of members they intend to recruit; what research they plan

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Progress check

Action points (cont/d)

to carry out; the type of information they propose to produce and disseminate. Monitor to see whether stated objectives are achieved and how far these meet the authority's own stated aims and objectives.

- **Develop specialist – separate – services which are tailored to meet the needs of particular groups;** but combine this with developing more equal access to existing mainstream services by groups who are currently low users. For instance, an authority might develop or fund others to develop specialist day care facilities for black elderly people while at the same time offering a wider choice of activities and catering within existing services.
- **Operate rigorous equal opportunities employment practices.**
- **Provide training for all staff on equal opportunities policy and practice.** Training could include the following elements: awareness of stereotyping and the impact of racism on carers and users; recognising differing family support systems; and understanding dietary and other practices of different black and minority ethnic communities.
- **Provide community care services in ways which make them accessible to all groups in the community** and which are consistent with equal opportunities policies. This requires sensitivity, creativity, and flexibility on the part of purchasers and providers.

Progress check

For further information on this issue, see Useful Reading, p.106 and 110.

Agreement between local and health authorities

> *Joint planning will be essential if the new planning arrangements are to work. Many authorities believe there should be joint plans ... as this would most efectively ensure the 'seamless' service which they would wish to achieve.*
> (Policy Guidance, para 2.2)

Local and health authorities have a responsibility to support carers, and in both cases there are services which could be described as examples of good practice. There are also instances of health and local authorities collaborating to joint-fund services benefiting carers and users, but there are still many obstacles to effective joint working, particularly at grass roots level.

Falling between the gaps

On the whole, carers are not that bothered about who provides a particular service, but they do care about quality and about what it costs them (or their relative) to use a service. The real problem for carers emerges when their needs remain unmet because no agency is able or willing to provide a service or because poor communication means that their needs are not even acknowledged. Gaps and discontinuities causing particular concern include: inter-agency arguments over who should provide assistance with bathing; disagreements about the provision of care after someone leaves hospital; and being passed from one agency to another, or being referred inappropriately. Problems can also arise for both carers and users where a long-stay hospital is closing but where health and local authorities fail to provide an integrated health and social care service for those who would formerly have used hospital services.

Towards a seamless service

The numerous debates about the boundaries of health and social care can seem meaningless to carers and users – and, indeed, to many front-line staff – a situation which is aggravated when discussions between health and local authorities seem primarily concerned with drawing up rigid lines of demarcation rather than working towards a 'seamless service' which would benefit users and carers.

Action points

- **Establish joint working groups of health and local authority staff** at an early stage in the planning process. Identify common values and principles for services for carers and users provided either separately or jointly by both authorities.
- **Draw up joint community care plans** which set out the respective contributions of health and local authorities.
- **Establish a joint planning forum** where unresolved issues can be addressed and possible solutions negotiated.
- **Joint fund posts for carers' officers** who will be responsible for assisting in the development of joint strategies and facilitating their implementation.

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Progress check

Action points (cont/d)	**Progress check**
☛ **Draw up service agreements** showing the respective contributions to be made by the health and local authority in relation to needs assessment and the provision of services to the different care groups and their carers. ☛ **Develop inter-agency and multidisciplinary training** and staff development to promote better mutual understanding and joint working. ☛ **Establish joint information data bases** wherever possible.	

For further information, see Useful Reading, p.110.

CHAPTER THREE: ASSESSMENT AND CARE MANAGEMENT

Introduction

The previous chapter looked at the part carers can play in shaping authorities' policies and plans for community care. We now turn to individual carers and how their needs and the needs of the people they care for will be met under the new arrangements – how authorities' assessment, care management and service delivery practices actualise their broad policies.

From April 1993, local authorities will be responsible 'for assessing individual need, designing care arrangements and securing their delivery within available resources' (*Caring for People*, para 1.12). These new arrangements are central to the government's thinking about community care, emphasising the importance of individually-based assessments and the development of care arrangements which reflect those individual needs. It is an attempt to move away from the present situation where people tend to be slotted into existing services and to move towards a needs-led service.

Where a person's needs are considered to be what the White Paper described as 'slight', advice and information may be all that is required from the local authority. But where someone needs ongoing help with personal care and domestic tasks, for example, then they will be entitled to a formal assessment of their needs. In other words, those people who are currently being supported by a carer will almost certainly qualify for such an assessment.

Disabled people and their carers need a range of services from both health and social service authorities. They may need someone to do the shopping, cooking, or cleaning. The disabled person may need help with bathing, dressing and other personal care tasks. Where demands on the carer are heavy, some form of regular relief from these responsibilities will be needed. The new assessment and care management arrangements are intended to establish what the needs of an individual and their carer are, what services they are entitled to and how these services are to be provided and by whom.

The new assessment procedures – if properly implemented – mark a major step forward in terms of putting carers and their needs firmly on to the agenda. In future, assessments will need to take into account the carer's needs and wishes and their 'ability to continue to provide care'; carers and users should be able to make choices and carers may ask to have their own needs separately assessed.

Recognising the carer's role and contribution

The government acknowledges that the great bulk of community care is provided by friends, family and neighbours (*Caring for People*, para 1.9).

Broad policy objectives are only a starting-point; they must be translated into actual practice; government policy is clear: 'assessment and care needs should always take account of the needs of the caring family, friends and neighbours' (*Caring for People*, para 1.11). In other words, any assessment of a disabled or elderly person must be undertaken in the context of the caring situation.

Relatives and friends of elderly and disabled people have always been the main providers of care in the home but their contribution has been largely hidden, unrecognised by service-providing agencies. In drawing up asessment and care management procedures, authorities must now consider the role of carers. They need to recognise that carers are not only providers of care but may also be service users themselves. They should be treated as 'partners in care' with the formal service providers but should also have their own needs for support acknowledged.

Carers require help to perform what is often a stressful and exhausting job, yet they may not feel they have the right to ask for help and support for themselves. Authorities need to make a firm and explicit commitment to providing support for carers in their own right in addition to providing direct services to those they care for.

Action points

- **Draw up a clear policy statement showing carers' rights** to have their own needs assessed and services provided in their own right.
- **Show how, and in what circumstances, the authority proposes to assess carers' needs.**
- **Spell out clearly the criteria which the authority proposes** to use when allocating services to carers and users.
- **Review how services are intended to help carers**. In the case of a day centre, for example, clarify what the respective benefits are (a) to users, and (b) to carers.
- **List those services which are primarily intended to meet the needs of carers**, and spell out the criteria for allocating these services.

Cont/d

Progress check

Action points	Progress check
☛ **Organise ongoing staff training** which promotes awareness of carers' needs and helps staff to implement policies relating to carer support more effectively. ☛ **Produce publicity** which is specifically aimed at carers and ensure that it receives the widest possible distribution to local carers.	

See Practical Initiatives, Examples 1, 2, 8 and 9, pp.81-95.

Approaching the authorities for help: the referral stage

Providing a user-friendly response

Local and health authorities are complex and bureaucratic organisations whose staff can all too easily forget this. The structures and processes with which they are familiar will almost certainly be foreign territory to those seeking help. Like anyone visiting a foreign country for the first time, clear maps and sympathetic and friendly guides are essential! Carers and users require a welcoming and positive response to enable them to obtain the information and services to which they are entitled.

Barriers to receiving services

An estimated one in four of all carers receives no help from service-providing agencies, and others get by with minimal external support. There are a number of reasons why carers do not use the services to which they and those they care for are entitled. A person may not see themselves as a 'carer' and therefore as entitled to ask for help. Alternatively, they may have sought help but had their request turned down, or been promised help which failed to materialise. Lastly, carers may simply not be aware that help is available.

Lack of appropriate and accurate information may mean carers fail to ask for help. Chapter 2 highlighted the importance of carers knowing what services are available and how they can access them. Information must include the answers to such basic questions as 'Where do I go for help?' and 'How will my request for help be dealt with?'. Without this sort of basic information carers can feel powerless, unable to understand how decisions are made about service allocation.

There are many different referral routes and carers may not necessarily refer themselves directly to the right place. This means that staff in other services must be kept informed and supplied with the necessary up-to-date information to enable them to refer people on to the correct agency or service. Health services staff, for example, whether working in hospitals or in community-based services, need to know how and where to refer people to the local authority if they are requesting an assessment of needs.

Gaining the carer's trust

'Getting it right' at the initial referral stage is absolutely crucial if carers are to develop a relationship of trust in service providers and are to feel confident that their request will be dealt with efficiently and sympathetically. Procedures must be drawn up for dealing with referrals so that people are not sent from pillar to post because they are being referred to the wrong place.

Understanding priorities

Carers are aware that limited resources mean that some services will be rationed. The information on how services are prioritised and the reasons why particular priorities have been selected needs to be made available to carers and users so that they have a realistic idea of what the authority can – and cannot – offer and why.

Carers approaching the local authority for help need to know 'the rules of the game', and, under the new arrangements, local authorities must publish a local guide to the principles and workings of the assessment procedure. This should include clear criteria for eligibility for assessment together with full information on how the process operates. So if, for example, an authority is planning only to assess those who may need residential care, then this needs to be clearly stated so that carers and users do not waste time seeking help which is not available.

When someone has referred themselves for help, they will want to know what happens next and when. They need to know what is likely to happen next and how long they can expect to have to wait before hearing anything further.

Action points

- **Provide information, targetted at carers, on who to approach** and what the authority's procedures are for dealing with referrals.
- **Devise clear procedures for handling new referrals** including establishing firm timescales for dealing with requests.
- **Publish a users' guide to assessment principles and procedures,** as specified in the NHS and Community Care Act).
- **Ensure that staff in all agencies (such as GPs, hospital and community health services) are supplied with up-to-date information on assessment criteria** and procedures as they are likely to be approached by carers and users requesting help.
- **Organise staff training programmes for direct-care staff** who will be dealing with requests for help from carers. Training should aim to ensure that staff treat carers sensitively and with respect and that requests for help are met by appropriate action within clearly spelled-out timescales.
- **Keep under review both your own authority's – and other agencies' – systems of referral** so that changes can be made where necessary. Staff who are in regular contact with carers and service users can provide useful feedback on any difficulties with current referral arrangements.

Progress check

See Practical Initiatives, Example 8, p.93.

Setting up the assessment

> *Assessing care needs should always take account of the needs of caring family and friends.*
> (*Caring for People*, para 1.11)

This guidance does not discuss how users of services should be assessed. Because our focus is on carers, we concentrate on the assessment of carers, which should not only acknowledge the contribution the carer makes as service provider, but should also take into account the carer's own needs – whatever those may be. However, identifying carers' needs, views and preferences should not be a substitute or alternative to assessing users' requirements.

What carers want from assessment

Carers have given some clear messages about what they want from an assessment. They are looking for a properly conducted interview, which should be informative; focus on their particular needs and the needs of the person for whom they are caring; recognise their role as a carer; explain what choices are available; and be held in private.

Separate or joint assessments

Carers are entitled to a separate assessment of their own situation and this should be made clear to them from the start. However, not everyone will choose this option and a joint assessment may provide an opportunity for the carer and the user to discuss their respective views on the situation and, perhaps, to do some re-negotiating on current arrangements. Issues like the need for respite care may need to be negotiated in a joint assessment, so that the possibly conflicting needs of carer and user can be resolved, or a satisfactory compromise reached.

Whatever decision is reached about a separate or joint assessment, both carer and user need to be clear whose needs are being assessed at the time. If the assessment is shared, then it will also be important to clarify whether or not the carer is speaking on behalf of the user and whether the user is clear that is the case.

Staff need to be aware that carers and users may want help in preparing for their assessment. Assessments are about creating a dialogue – between the carer and/or user and the authority's worker – which enables them to put across their views about their needs and wishes. This may take place over several visits and it is the staff member's responsibility to make this process as relaxed as possible. Carers and users should be told about who else may have access to the information that they provide. (This can be a particularly sensitive issue where the carer has a mental health problem and where the carer may feel that confidentiality is essential in order not to disrupt further what can often be difficult family relationships.)

Some carers and users may decide they want someone to be present at the meeting who can act as their 'friend' or 'advocate' and help them present their case. (This is discussed in more detail in Chapter 2, pp.25-27.)

Finally, wherever possible, different authorities in the carer's area should be able to offer them a single assessment. Health and local authorities should be working towards a unified assessment process – a move which would be welcomed by both carers and users who find multiple assessments tiring and stressful. Information should be transferable between agencies provided the carer and user have given their permission.

Action points

- **Ensure that your authority's local guide to assessment principles and procedures provides all the information that carers** and users need prior to their assessment.
- **Consult on your written guide to assessment with local carers and users,** revise in the light of their comments, and pilot with carers and users.
- **Set up training for staff undertaking assessments** which will develop their awareness of carers' needs and help them to work more sensitively with carers.
- **Develop guidance for staff undertaking assessments** so that they can draw out both positive and problematic aspects of people's individual situations. Specific trigger questions to be asked in discussion with carers can usefully be suggested.
- **Draw up clear rules regarding confidentialty**. Carers and users need to know what rules of confidentiality apply to assessment interviews and who will have access to any information they may provide.
- **Allow for the fact that a thorough and comprehensive assessment may require several interviews** in order to gain a full understanding of the situation and to elicit fully both carers' and users' needs and wishes. However, the same agency worker should be involved throughout.

Cont/d

Progress check

Action points (cont/d)

- **Ensure that both carers and users clearly understand why the assessment is being undertaken** and how it will be conducted. Be prepared to offer verbal as well as written explanations before the assessment takes place.
- **Ensure that staff carrying out assessments are able to provide carers and their relatives with full information** about services and benefits to which they are entitled.
- **Give carers and users the opportunity to speak privately with the person carrying out the assessment** if they wish to do so, and the information given should be treated in confidence if the carer or user so requests.
- **Inform carers and users that, should they wish to do so,** they can ask a friend or advocate to attend their assessment interview and help them put over their case.
- **Ensure that choices about services are clearly explained** to carers and that carers receive enough information about the options available to them to enable them to make informed choices.
- **Allow the carer to choose where the interview takes place,** bearing in mind that some prefer to be assessed in their own home but others will prefer to meet elsewhere.
- **Give the carer in writing the name and telephone number of a contact person,** together with an indication of when they may expect to hear the outcome of the assessment.

Progress check

See Practical Initiatives, Examples 7, 8 and 11, pp.91-98.

Listening to carers and offering advice

> *The preferences of carers should be taken into account.*
> (Policy Guidance, 3.28)

Listening

Pointing out that carers should be listened to may seem to be stating the obvious but carers are not used to being listened to. Professionals have rarely addressed the carer's needs, being more used to thinking in terms of service users. Professionals need to hear what carers have to say about their own needs, about their experiences of caring and about how they feel about community care services.

Carers may never have been asked for their views before and so may not find it easy to formulate their ideas and communicate these to other people. Or they may have been asked for their views, but what they had to say was ignored or rejected. A sensitive and caring approach is needed to help carers think about their needs and how these might best be met. Assessment is definitely not about professionals going in with a pre-prepared package of services, and the idea that carers can either 'take it or leave it'.

Offering advice

Having listened to what carers have to say, and helped them begin to think about how services might meet their needs, staff carrying out assessments must be able to offer sound information and advice about available services. Carers and users need to be able to make realistic choices. Where no service exists to meet a particular need, then staff must make it clear to carers and users that this is the case and that they will be notifying service planners and policy-makers. Where a suitable service is available, carers and users need to know whether it is free, if not what it costs, who it is targeted at, whether they would be eligible to use it and how it might benefit them.

The role of staff in assessment is essentially an enabling one. By listening, clarifying and offering advice and information, staff should help carers and users to define their own needs and, with available information, to determine with the person carrying out the assessment how those needs might most appropriately be met. With the support of staff, carers and users should be assessing their own needs. Assessment is not something which other people do 'to' or 'for' them.

Whether or not the carer has opted for a separate assessment, staff carrying out assessments need to listen carefully to what each is saying, identify areas of agreement and disagreement, or conflict of interest between carer and user, and help both to negotiate care arrangements which satisfy both parties.

Carers need to feel they can express their views honestly and openly without fear of censure. They need to be able to criticise services without fear of being branded a 'troublemaker' and without having to worry that they or the person they care for will be penalised in some way. They need to know that their comments and views will be fed into the next review of services.

Action points

- **Devise a code of practice for staff carrying out assessments** and organising service provision. Emphasise the active role which carers and users will have in articulating and assessing their own needs.
- **Listen to what carers have to say about the help required** by the person they are caring for. Recognise their knowledge and expertise gained from day-to-day caring – but also be prepared to hear users expressing differing views at times.
- **Work alongside carers' organisations to enable carers to help one another to prepare for assessment interviews** and to help them achieve the best outcome.
- **Provide training for people carrying out assessments to develop mediating and negotiating skills** so that they can help carers and users resolve any conflicting views, needs and wishes about the services they require.

Progress check

See Practical Initiatives, Examples 7 and 8, pp.91-93.

Meeting the needs of black and minority ethnic carers

> *Authorities also need to ensure that assessment is accessible to people from black and minority ethnic backgrounds.*
> (Policy Guidance, para 3.21)

Barriers to receiving service

Black and minority ethnic carers face particular difficulties in gaining equal access to support services from health and local authorities. This may be because they are unaware of available services or they may know about existing services but find they do not meet their particular needs arising from their religious or cultural customs. Officaldom can seem off-putting and because services tend to be offered on a 'take it or leave it' basis, the low uptake of services by black and minority ethnic carers is then used to justify the inaccurate and misleading assumption that 'they prefer to care for their own'.

Organisations representing the interests of black and minority ethnic communities may have made representations to service providers, pointing out that current services do not meet their needs, but on the occasions where some action is taken to improve the situation, inappropriate responses can mean that take-up continues to be low. If service providers have failed to consult adequately with potential users of a specialist service for black and minority ethnic carers and service users, they may be providing something which cannot meet people's needs and wishes.

At an individual level, carers may experience racism or discrimination within service-providing agencies – either from staff or from other users. This may take the form of off-putting and generally unwelcoming behaviour, or there may be more indirect discrimination – by providing an inferior service, for example, or one which does not permit users and carers to observe their religious or cultural practices.

A non-specialist service – a day centre, for example, may have a policy of serving people from diverse ethnic and cultural backgrounds, but if there is, say, only one Asian user, and no staff member speaks that user's language, then the service is not meeting the needs of its local Asian population in an appropriate fashion.

Specialist or mainstream services?

In some areas, voluntary organisations run specialist community care services for members of black and minority ethnic communities. Although these may be appropriate in some cases, authorities should continue to seek ways of making their mainstream statutory services more sensitive to the needs of black and minority ethnic users so that their needs are not met exclusively by the voluntary sector.

Action points

- **Review how your authority's assessment and care management practices** will meet the needs of black and minority ethnic carers.
- **Use bi-lingual staff** wherever this is possible for assessments of carers and users whose first language is not English. Otherwise use trained interpreters.
- **Take account of any special requirements** relating to religious cultural practices such as diet, when drawing up care arrangements for individuals.

Cont/d

Progress check

Action points (cont/d)

- **Draw up anti-racist practice guidelines** for assessment which specify how the assessment process is to be conducted.
- **Grant-aid or contract with voluntary organisations providing specialist services for black and minority ethnic carers** and users. However, these should not preclude authorities changing their mainstream services so that they become more responsive to the needs of black and minority ethnic carers and users.
- **Consult widely with black and minority ethnic carers** about their needs and about how they would like these needs met by services. Provide feedback on what action the authority proposes to take following consultation and monitor this regularly.
- **Monitor the take-up of services by black and minority ethnic carers** and users and set targets with clear timescales to increase their use of mainstream services.
- **Ensure that the authority's equal opportunities staff recruitment policies are fully implemented.** The racial background of assessment and care management staff should reflect the composition of the local population.

Cont/d

Progress check

Action points (cont/d)

- **Produce your local guide to assessment principles and procedures in non-English languages** to meet the needs of local black and minority ethnic communities.
- **Target publicity about support for carers at black and minority ethnic communities** through appropriate media such as specialist radio programmes or non-English language newspapers.
- **Acquire nationally produced guides for carers aimed at Asian and Afro-Carribean communities**, inserting local information where appropriate.

Progress check

Practical Initiatives, Examples 4 and 10, pp.87-88 and 96-97.

For further information on this issue, see Useful Reading, pp.106, 107 and 109.

Form-filling

It is often the bureaucratic practices of service providers which deter carers from seeking help. Every time a carer or user wants to obtain a particular service or claim a new benefit, they will almost certainly have to fill in a form, go through an assessment and prove they are a carer.

Avoiding unnecessary duplication

Each organisation will want to check a person's entitlement to services, but sometimes even departments within the same organisation will carry out separate checks. Where two different organisations are concerned, combining their referral and assessment systems may not be possible. However, even if the establishment of single transferable referral and assessment procedures is still a pipe-dream, authorities should do everything they can to minimise the paperwork with which carers have to deal. Carers and users should not have to answer the same questions on several occasions to different service providers.

As we move towards a more pluralistic system of care where a carer and user within one family may well be receiving different services not only from community health and social services, but also from services contracted with voluntary and private providers, every effort must be made to ensure that as service recipients they are not endlessly filling in forms for different agencies.

Action points

- **Develop joint forms for asesssment** or other information collection.
- **Agree common standards for data collection** and record-keeping where shared record-keeping is not feasible.
- **Make sure that forms are written in plain English.**
- **Offer help to carers with completing forms** where this would be appropriate. Use bi-lingual staff or interpreters to help people whose first language is not English.
- **Ask only those questions which are necessary** in order to provide the service being requested when asking carers to complete forms.
- **Draw up clear policies and guidelines on confidentiality** and ensure that carers are aware of these when being asked to supply personal information.

Progress check

A single-contact person

> *Where service users and carers are not provided with a single care manager, there should always be a nominated worker to act as the primary point of contact.*
> (Policy Guidance, para 3.12)

Carers and users who rely on a number of different services to meet their needs for support may find themselves dealing with a bewildering array of different people. They may find that despite contact with several different workers, no one person takes overall responsibility for co-ordinating their package of services. When their individual circumstances change, or in an emergency, carers may be passed from one person to another with everyone passing the buck and no one prepared to take responsibility for sorting out the situation.

Under the new arrangements, care managers may be assigned to people whose needs are particularly complex or who require a high level of resources to meet their needs. But even where someone does not have a care manager, the Government's advice is quite clear: 'there should always be a nominated worker to act as a primary point of contact in resolving any difficulties, even if that worker changes in the course of the case management process'.

The idea of a single contact person is welcomed by many carers; as one person put it, they would like to know that there is 'one person in charge of the whole lot'! However, this should not stop a carer or user asking for a different key worker or care manager to be involved with their situation if they are not happy with the decisions being made by their current worker.

Action points

- **Ensure that, following the setting up of care arrangements,** the carer and user should have access to a contact person and should be given their name and telephone number in writing.
- **Designate a care manager** for people whose needs are complex and who require a high level of services.
- **Consider whether in some instances** it would be appropriate for the carer and user to each have their own separate care manager or key worker.
- **Ensure that all carers have either a designated care manager or a key worker.**
- **Provide the carer with the name of a second, back-up person** who can provide cover when the care manager or key worker is not available (annual leave, sickness, study leave).
- **Draw up local arrangements for designating care managers and key workers.** Wherever possible this should be carried out as a joint exercise between health and social services.

Cont/d

Progress check

Action points (cont/d)

- **Draw up local guidance on how care managers and key workers** are to consult and communicate with workers from other disciplines or agencies.
- **Carers may wish to act as their own care manager** or they may wish to have access to an independent care manager and this should be supported by authorities.

Progress check

Written agreements and care plans

> *The care plan should be the result of a constructive dialogue between service user, carer, social services staff, and those of any other agency involved.*
> (Policy Guidance, para 3.28)

Government policy is quite clear. Following an assessment, a written agreement – described as a 'care plan' – should be drawn up, specifying what services are to be provided, by whom and when. Care plans should include details of whatever services the carer has agreed to provide for the person they are supporting. The plan should also record any assessed needs the authority (or other agencies) are currently unable to meet and the reasons for these service deficits.

Carers and users can find that they have had their needs assessed, and services have been arranged with no information being offered formally to them about who is to provide the service, what the user and carer may expect from the service, and what the expected outcomes are. Having a written agreement showing what the carer and services providers will each contribute to the 'care package' provides an opportunity for carers and users to complain when and if service providers fail to deliver the services they have agreed to.

These written agreements are also useful for monitoring changes in people's circumstances and assessing the extent to which services packages have been changed to reflect this. Where gaps in current provision are noted in the agreements, these can be used by authorities to inform service planning and to develop new provision when resources allow.

Action points

- **Inform all carers that they can request a separate care plan for themselves** which focuses on their own needs and how these will be met.
- **Provide carers with a written care plan following assessment.** This should state clearly which services will be provided, who will provide them and when the carer can expect to start receiving each of the stated services. If any delay is anticipated, this should be stated and the reasons for this given.
- **Include details in the care plan of the review mechanism** which the authority is proposing to use to take account of any changes in either the carer's or the user's circumstances. Care plans should never be regarded as static documents.
- **Specify in the care plan where no services are currently available to meet an assessed need,** the reasons for this, and when it is envisaged that the service deficit will be rectified.
- **Make care plans available in the appropriate language,** when the carer's and user's first language is not English. People with sensory or learning disabilities may require a care plan in Braille or on audiotape.

Cont/d

Progress check

Action points (cont/d)

- **Enable users and carers to hold** – or have easy access to – their own records.
- **Include in the care plan the whole care package,** even where this involves inputs from other agencies in order to give carers and users as much information as possible.
- **Include in the care plan a description of the services** which the carer is currently providing.
- **Provide carers and users with the opportunity to read and comment on a draft version of their care plan** to ensure that they agree with its contents and can incorporate their own comments, should they wish to do so.

Progress check

Complaints

In accordance with the NHS and Community Care Act (1990), all local authorities should have had a formal complaints procedure in place since April 1991.

Barriers to using a complaints system

Carers may be dissatisfied with the services which they and/or the person they are caring for are receiving, or may feel that services they need are not being provided. However, they are often reluctant to complain. They may be afraid that any criticism will lead to the service being withdrawn or they may not want to be labelled as a troublemaker. At the same time, though, they may also feel that any criticism cannot really be justified because they should be grateful for any help offered.

Even where carers have complained, they have frequently found that their complaints were bypassed or ignored and no action was taken by service providers. This left them with only two options – to carry on using an unsatisfactory service or to stop using the service altogether.

Action points

- **Operationalise complaints procedures as an important and positive means** of enabling carers' and users' voices to be heard.
- **Provide training to staff members operating complaints procedures.** This will help them to develop a sensitive approach to handling complaints either using informal problem-solving or the more formal procedures.
- **Inform carers that they may ask someone to speak on their behalf** and represent their interests when they are using the complaints procedure. See pp.25-27 on advocacy.
- **Provide funding and/or other forms of support** to carers' groups and voluntary organisations providing advocacy services.
- **Establish clear timescales for handling complaints** and include this information in all publicity material for carers and users.
- **Produce leaflets about the complaints procedure in languages other than English** where there is a local need for this.

CHAPTER FOUR: PUTTING PLANS AND PROCEDURES INTO ACTION

Health and local authorities are expected to improve support for carers at a time when those authorities are undergoing major organisational and managerial changes, operating within considerable resource uncertainties. These changes and uncertainties can be no excuse for soft-pedalling on carers' support as this issue is central in a new vision of community care. In this respect, the starting point for change must be the needs of people requiring care *and their carers*.

While developing this guidance, we have witnessed the extent to which some authorities are building carers' concerns into their new community care arrangements. Some are building on approaches and activities undertaken before the Government identified improved practical support as a key objective of the community care reforms. Others seem to have been encouraged to make a start, having been prompted by the NHS and Community Care Act. Changes in ways of working with carers in mind are taking place, from different starting points and at a varying pace.

We are aware that some of the changes – important though they are – are invisible to carers. Policies, plans and procedural advice to workers are all very well, but they need to be implemented if carers and the people they care for are to notice any change in their lives. The real challenge facing authorities is to keep up the pace of change and to achieve concrete improvements which have an impact on people's daily lives. In facing this challenge, it will help to hold on to some key issues which will determine how change is implemented.

Strong leadership at national and local levels

There has, of course, already been a strong lead from the centre, directing attention towards better support for carers. That lead was weakened when the decision was made to delay implementing fully the NHS and Community Care Act until 1993. However, it is encouraging to see that carers' issues are to be considered in the review process set up by Government to monitor the phased implementation of new community care arrangements. The six-monthly progress reports which will be compiled by the Social Services Inspectorate and regional health authorities will expose the extent to which carers' concerns are being addressed at local level. We have yet to see what action will be taken when progress on consultation and service planning is deemed to be unsatisfactory but it is, nevertheless, a hopeful sign that carers have not been forgotten in the review framework.

The most crucial issue requiring leadership from Government relates to the planned transfer of resources in 1993. In the meantime, close scrutiny of problems arising for carers and users is required as new systems and procedures in community care are put in place. Urgent remedial action will be required to ensure that, at the very least, their situation should not deteriorate during this transitional period.

Local leadership is equally important. The commitment and creativity of authority members and senior managers is essential if carers are to receive a better deal. This leadership has been particularly evident in those authorities who have placed carers firmly on their policy and practice agenda. It will become even more necessary as tough decisions have to be made on priorities. It is unlikely that these decisions can continue to be fudged, even when (and if) resources are increased, as planned, in 1993.

Staff training and development

New community care arrangements will require major shifts in attitudes and working practices from top to bottom in organisations. If carers' concerns are to be taken seriously, workers will need to be more aware of their needs as well as the needs of users. They will require new skills to equip them to work in new ways which empower carers and users. Investment in training will be a vital component of implementing change.

Participation of carers and users

Carers and users are clear about the changes they would like to see put in place. They have a real interest in seeing that proposed changes do take place. Their participation in the implementation of change provides a vital push, while at the same time ensuring that workers are able to keep close to the concerns of people using services. There is not, of course, one model which can be adopted to ensure that carers and users are empowered and able to have more control over their lives and the services they require. However, there is much to be gained by learning from experiments taking place in different parts of the country and building on these to achieve a real partnership with carers and users.

There will inevitably be upheaval in the next year or so and there is always a danger that carers and users will end up with fine words but no change. This need not happen, as we have seen among those authorities who have created new opportunities to build a more carer-sensitive community care. The gaps between policy and practice can be closed but, at the end of the day, it will be the real changes in services which have to be the baseline for judging whether carers and the people they care for have gained anything at all from the reforms.

EXAMPLES OF LOCAL PRACTICAL INITIATIVES

This section contains examples of carer support developments in different parts of the country. They are documented to show progress already made in addressing carers' concerns. In some cases, the initiatives described are at a very early stage of development where practical outcomes for carers are not yet clear. However, we believe that, in total, the examples illustrate the ways in which the map of carers' support initiatives is being redrawn within the statutory sector.

We suspect that none of the agencies listed would claim that they have 'got it right for carers' yet. However, they all, in their different ways, are working at it, learning as they go. All are willing to provide further information and to share this learning with others; therefore, contact names and addresses are given under each example.

Examples include the following:

Policy development

Consultation

Information

Assessment and care management

Advocacy

Service development

Carers' organisations

Policy development

(1) **Hampshire County Council** has developed a carers' support policy which consists of a broad policy statement and a set of operational principles.

Policy statement

This is the foundation stone on which the Social Services Department, in conjunction with carers, can build and develop an integrated service providing support for carers.

- It is recognised that community care is a partnership in which carers, by their central position in providing 'the great bulk of community care', should be respected, valued, consulted, enabled and supported in this role by this department and its agents.
- This community care partnership between service providers and carers will be developed to benefit the carers and those for whom they care, recognising that carers have needs as individuals.

Operational principles

- *Recognition*

The contribution of carers to the delivery of community care will be recognised and their independent needs will be assessed and met as appropriate.

- *Consultation*

Carers will be listened to and consulted in the development and delivery of policies and services.

- *Choice*

This department will not presume that any individual will fulfill the role of the carer. Opportunities will be provided to explore alternatives appropriate to the individual circumstance of both the carer and cared for person.

- *Information*

Information will be made available to carers on all aspects of services provided by and known to this department.

- *Practical services*

To seek to deliver practical services in the home and community to assist with the caring task, based on the needs of the carer irrespective of gender, age or race.

- *Respite*

To seek to provide a range of respite for varying time periods and in varying locations, which will suit individual need.

- *Support*

To promote a range of support services to meet the emotional needs of carers, including counselling, suitable to individual need.

The starting point for developing a formal policy was the Carers' Charter (see page 105 *Carers' Needs: A 10 point plan for carers*). Issues arising from the Charter were discussed at a series of conferences. With support from the Chair of the Social Services Committee and the Director of Social Services, the policy was further developed in consultation with senior managers and other staff in the department. Carers and carers' groups were also consulted by writing to every group known to exist in the county (55 at that time), and by visiting 14 groups for detailed discussion and debate. Following these consultations with carers, two key sections of the operational principles (Choice and Services) were completely redrafted.

All those consulted were sent a final copy of the policy, highlighting the changes which had been made in the light of carers' views. The newly adopted policy was publicised through local newspapers and television and radio stations in the county.

Contacts for further information:

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Carers Development Officer

and

Sally Gunn
Carers Support Officer

Hampshire County Council
Social Services Department
The Castle
Winchester
SO23 8UQ

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(2) **Yorkshire Regional Health Authority** has developed a policy on carers' support. As a result, policy guidance for district health authorities and family health service authorities was issued in 1991. The RHA's Priority Services Group adopted a 'bottom-up' approach to the policy development.

The Group began by conducting extensive discussions with individual carers and groups and with statutory and voluntary agencies in one locality. (Bradford was chosen for its multi-cultural diversity and the fact that a wide variety of services were in place.) These discussions, together with a literature search and consultations with national organisations and academics, enabled the Group to identify the problems carers experience and the range of services they require. After this information gathering exercise, a first draft of the policy was drawn up. This was sent out to over 250 statutory and voluntary organisations (including carers' organisations) in the region for consultation. Revisions were made in the light of the consultation exercise, and the RHA then endorsed and adopted the regional policy on carers.

The policy outlines the types of services which should be made available to carers by primary and community health care practitioners, by hospitals and other agencies. It also sets out the principles on which services should be based, which are: Involvement (of carers); Consistency; Reliability; Flexibility; Choice; Access.

The policy sets out the region's expectation of health agencies and professionals in providing support to carers. To encourage policy implementation, seven key areas of action have been recommended.

- Nominate a senior manager who will have responsibility for reviewing, developing and co-ordinating services for carers;
- Include in community care plans the local arrangements for developing services with the full participation of carers;

- Ensure that the new assessment procedures include a requirement to record carers' views and needs in the documentation;
- Initiate discussions with voluntary and other statutory agencies on how to co-ordinate the provision of information for carers;
- Practical measures to be taken to ensure that carers can attend appropriate meetings;
- In collaboration with local authorities, DHAs to develop timely and appropriate services for the provision of equipment which are sensitive to local needs;
- Establish service agreements between agencies to meet the respite needs of carers.

Contacts for further information

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and/or

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Park Parade
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(3) Before drawing up its policy statement on carers, **Tameside Metropolitan Borough Council** Social Services Department undertook two major local surveys. The first, carried out during 1987, was a random survey of 1700 homes and the follow-up exercise in 1988 involved in-depth interviews with some 800 carer households.

The surveys found that 11 per cent of all adults in Tameside are carers and 16 per cent of all households are carer households. The research put carers' needs into sharp focus. As a result, carers have become one of the Council's top five priority groups for services in the Borough. In the words of the policy statement: 'We are prepared to say that the needs of carers are a priority'.

The Borough Council has accepted that carers are important members of the local community and their policy on carers acknowledges that:

- carers have needs in their own right;
- being a carer is stressful;
- carers are potential social services clients; and
- carers are also 'partners in community care'.

Contact for further information

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OL6 6DL

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Consultation

(4) **Birmingham City Council**, in collaboration with health authorities and other service-providing agencies, has been systematically consulting carers since 1987. A series of neighbourhood meetings have been held annually to find out what local people think of services and what changes they would like to see. Senior officers attend the meetings to hear at first hand what carers have to say.

Approximately 650 carers have been consulted over a three-year period. Efforts are currently concentrated on reaching 'hidden carers', including those in black and minority ethnic communities. Although efforts have been made to reach black carers during the past four years, the model used for consultation has met with limited success. Other methods are therefore being used to address this by working more closely with black community workers. With the help of these workers, meetings aimed specifically at black carers are now being held at day centres and with support groups to find what out the experiences and views of black carers are.

Issues raised by carers have been used to identify a list of action points, focusing on improvements needed in information services, day and respite care, equipment and transport, reliability and availability of services. Individual chief officers have taken personal responsibility for implementing specific action points. Progress is monitored by a Community Care Performance Review Group. A Carers' panel has also been convened to enable carers to participate in monitoring service changes. Feedback on progress is provided for all carers who have been consulted, through a newsletter and regular meetings.

A Carers Unit has recently been set up within the Neighbourhood Offices Network. The Unit offers a corporate approach to carers' issues. It takes the lead in ongoing consultations with carers and encourages a programme of special events and information activities through the City's 43 Neighbourhood Offices.

Information gathered through the consultation programme has been fed into the City Council's first Community Care Plan. Formal consultations on this Plan will be undertaken during 1991, using established consultative mechanisms and structures.

Contact for further information

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Principal Neighbourhood Officer
Birmingham City Council
Neighbourhood Central Unit
Council House
Victoria Square
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Tel: (021) 235 2303

(5) Two Carers' Forums have been developed by the Social Services Department in **Gloucestershire** in response to carers' support groups wanting more contact with each other. This initiative was made possible by the Social Services' imaginative creation of the posts of 'Disabled Persons Act social workers', whose role includes working with carers.

With support from local and health authority officers, Forum members have worked together drawing up an ideal model of services and producing a report on their needs. Service managers have been invited to Forum meetings to talk about new developments and to hear what carers have to say about current services and future plans. Revised plans have then been taken back to the Forums for their further views and suggestions. Forums serve as a focus for the issues and concerns of carers; this had led to other developments, including the co-ordination of training for care workers and carers, a carers' newspaper, and a 'philosophy document' aimed at raising the awareness of carers' rights and needs in all service-providing bodies. Another important aspect of the forum's work has been the lobbying of elected members and service managers.

A structure has been established for ongoing consultations relating to community care developments, with authority members and officers meeting carers, both in individual support groups and in the two Forums.

Contacts for further information

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INFORMATION

(6) **The London Borough of Sutton**, in collaboration with Merton and Sutton District Health Authority, has been trying out different ways of improving information services to carers, including encouraging professionals and other staff to act as information givers.

A series of 'carers' craft' courses has been organised to provide carers with information about services and to offer skill training in areas such as lifting, incontinence, etc. Local newspapers have been used to publicise practical initiatives benefiting carers. Posters drawing carers' attention to sources of information and support have been placed in all GP surgeries and health centres. Several thousand copies of the carers' handbook *Caring at Home* (see page 107) have been purchased and distributed to carers in the area. The local Citizens' Advice Bureau was funded to provide a carers' telephone helpline and home visiting service. Leaflets have been distributed which give details of services such as home care, with the address of the relevant office and a telephone number to contact in order to ask for help. These leaflets are also available in Asian and Chinese languages.

Induction courses for nurses and all new social services employees now include carers' awareness training. Development staff have also worked with GPs and their receptionists to test out ways of improving information for carers in the general practice.

Contact for further information

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Programme Coordinator, Sutton Carers Project
Sutton Social Services Department
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St Nicholas Way
Sutton, SM1 1EA Tel: (081) 770 4554

Assessment and Care Management (The Assessment Interview)

(7) **Oxfordshire County Council** adopted the Carers' Charter in 1989 and a Carers Unit was established in 1990 to develop services for carers and to provide advice and advocacy for them. The service is publicised through local advertising, through professionals informing carers they come across, and through the local carers' forum.

Assessments of carers' needs, which are undertaken by two of the Unit's workers, are either carried out over the phone through the Unit's telephone advisory service, or the worker will visit the carer's home. When a carer asks for help they may be requesting a particular service or resource; however, the majority of carers contacting the Unit, while they may be aware of what their needs are, have no idea what help or support is available.

The aims of the assessment interview – whether it is an initial interview or a review – are to identify and clarify the problem, to provide the carer with a range of information to enable them to make an informed choice; and, where appropriate, to act as the carer's agent', representative, or advocate to help them obtain the service they require. Following the assessment, the carer will be referred on to the appropriate agency which may be in either the statutory or independent sectors.

A copy of the completed assessment form is sent to the carer. A review is carried out two months later using a brief questionnaire to monitor whether services have been provided, whether the carers are satisfied with them, and whether services have been appropriate.

Contact for further information

Sheila Taylor or Pat Southcott
Oxfordshire County Council Carers Unit
Yarnton House
Rutten Lane
Yarnton
Oxfordshire
OX5 1LP

Tel: (08675) 70278

(8) **Doncaster Social Services Directorate** has produced a discussion document on policy and practice arrangements for their assessment procedures. The statement of intent makes it clear that carers' needs must be considered fully and 'wherever appropriate, the assessment will separately accommodate the views of the carer in order to determine the level of service or support they require in their own right'.

A self-assessment form is under consideration which would be sent out after someone has made a preliminary enquiry about services, either over the telephone or face-to-face.

In the current draft, there is – for the first time – a separate form seeking information from carers. Carers are asked to provide brief details about their situation, including other responsibilities they have (in the family, at work); whether anyone else helps in the caring and, if so, what they do; their own views on extra help needed; the extent to which they are able to leave unattended the person they care for; medical or other reasons making it more difficult to look after the person needing care.

The discussion document, including the proposed self assessment forms, is currently being discussed at multi-agency meetings. When amended, a proposal will be put forward for formal approval.

Contact for further information

Joseph Rowntree
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Doncaster Social Services Directorate
Frenchgate Centre
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DN1 1PH

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(9) **Birmingham Social Services Department** believes that carers have a vital part to play in the assessment process. Carers are seen as making a contribution in the assessment of needs of those they care for, and should be able to have their own needs separately assessed. The department is currently revising its assessment form to include carers.

Birmingham's principles of assessment include the following:

- each person is an individual with a right to participate fully in decisions about their own needs. This means making clear distinctions between users' and carers' needs.
- the religious and cultural needs of users, families and carers must be understood and respected.
- the confidentiality of users and carers must be respected.

The Council's assessment procedures will be based on the following operational principles:

- all requests for assessment must be acknowledged within five working days.
- inform the user and carer of the procedure to be followed and how long it will take.
- inform the user and carer who is carrying out the assessment.
- tell carers of their own right to an independent assessment.
- ensure that users and carers take a full part in the assessment, and have the opportunity to define their own needs, including those needs which are different from those defined by the assessor.
- make sure that the user or carer concerned agrees to an assessment being made.
- arrange for the user or carer to have access to the completed assessment if they wish.

Piloting is now underway to test the effectiveness of the assessment form as a tool for finding out the needs of both users and carers and its appropriateness. Extensive consultation to include carers' groups will take place in conjunction with the piloting.

Contact for further information

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Birmingham City Council
Social Service Department
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(10) In 1990, four pilot projects were set up in **Gloucestershire** to test out different ways of implementing care management systems. These projects were funded by the county's Social Services Department, the two District Health Authorities and the Family Health Services Authority.

Results currently being studied indicate that while there were lessons to be learned from the different projects, none of them would, in their present form, meet the needs of the black and minority ethnic communities in Gloucester.

As a result, and with financial support from the King's Fund, it was decided to set up a special two-year care management project which would be sensitive to the particular needs of the Afro-Caribbean, Asian and Chinese communities who comprise the main black and minority ethnic communities in that area. The multidisciplinary project, in which representatives of local black and minority ethnic communities are involved, employs three care managers – one from each of the three communities mentioned above.

The project has four main aims:

- to provide individual packages of care for those in need of a range of services in a way which is flexible and offers choice;
- to establish, through individual assessment, the needs of the black and minority ethnic communities in Gloucester and how they might be met in future;
- to actively inform the communities about services; and
- to develop services where there are no existing services or where the existing service is inappropriate.

Contact for additional information

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Social Services Department
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GL12TR

Tel: (0452) 426848

ADVOCACY

(11) **The Carers' Centre in Hove**, East Sussex, which opened in 1988, offers a range of support services to carers. The Centre is currently funded by the Social Services and Health Authority Joint Finance Programme.

One of the most important aspects of the Centre's work is listening to the needs of carers, providing appropriate information on entitlements and available services as well as helping carers identify their needs. This is done on a flexible, drop-in basis to fit in with the individual carer's own timetable and free time.

Many carers are unsure what information they need or what options may be available to them. Staff at the Centre are able to listen to what carers have to say about their situation and suggest services they may not know about.

After listening to what a carer says he or she needs, staff will prepare a 'shopping list' of what the different agencies can offer, marrying this to what carers themselves want. The Centre will then either advocate on behalf of the carer for the services they need or prepare the carer to put their case forward. The Centre's up-to-date and accurate information helps carers make informed choices and explore any options that may be open to them.

Contact for further information

Helen Bashford
Carers' Centre
First Floor
210 Church Road
Hove
BN3 2DJ

Tel: (0273) 207879

(12) Since 1989, the **London Borough of Hillingdon** has been developing its work on carers' support, based on Section 8 of the Disabled Persons Act. Two carers' advisers are based in the PPSD (People with Physical and Sensory Disability) team. Much of their work involves advocating on the behalf of carers in the following ways:

- Representing carers' views through various multi-agency committees and community care forums. Regular meetings are held with the local carers' development officer, employed by Carers National Association (this post is sponsored by the London Borough of Hillingdon Social Services Department). The carers development officer, an independent worker, encourages carers' participation on several of these committees/forums.
- As service brokers, helping individual carers to identify the services they need and acting with them or on their behalf to obtain those services.

Good links are maintained with the voluntary organisations for advice, information and referrals. The carers' development officer from the Carers National Association and the statutory carers' workers meet regularly to pinpoint areas of carers' needs.

Contacts for further information

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or

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UB7 7QJ

Tel: (0895) 431432

SERVICE DEVELOPMENT

(13) **In Doncaster**, a two-year service development project, supported by the King's Fund Carers Unit, has enabled local carers and staff from social services, health and housing to find ways of making existing mainstream services more responsive to carers' needs.

In the first phase of the project, carers and front line staff from the various agencies and departments worked together to identify changes needed in the way services were currently operating. New ways of working to accommodate carers' concerns were subsequently tried out. Throughout, managers and supervisors took an interest in the ideas put forward and supported their staff as they put those ideas into practice. Changes which were piloted included more flexible work times and tasks to suit carers' and users' preferences; increased information-giving and improved record-keeping; improved referral procedures to keep carers informed of progress in dealing with their requests for help and to enable them to telephone a particular contact number for further information; and social events which enabled staff and carers to get to know each other better.

Encouraged by the receptiveness to change and the initiative shown by frontline staff, development work continued with service managers and supervisors, in order to bring about improvements on an area-wide basis. Locality managers considered policy developments concerning carers and examined how current carers' initiatives might be built on while, at the same time, overcoming the principal barriers preventing sensitive support to carers, addressing the main policy and resources barriers preventing more effective support to carers. Strategies for implementing change in the assessment of carers' needs and the allocation of services were devised.

At the time of writing, the results of this development work were being evaluated, and plans for continuing carer-focused developments were being devised.

Contacts for further information

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and

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Principal Officer
(Adult and Elderly Services)

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(14) **In the London Borough of Sutton**, the Social Services Department has been reviewing and changing its community services giving careful consideration to carers' needs. Like many other authorities, it has developed 'special' home care schemes within its general home care service. 'Add-on' schemes offer crisis care for a two-week period free of charge, and intensive personal care and domestic help seven days a week. These schemes have assisted elderly people living alone and those who live with caring relatives.

The extent to which the general home care service has assisted carers was not clear until a thorough review was undertaken. An increasing case load and limited resources had led to the practice of allocating a few hours a week to large numbers of people, most of whom did not live with carers. A home care survey was undertaken, using independent researchers. The aim of the survey was to ascertain carers' use of the service, the nature of the service they received, and how carers viewed the service. Carers not receiving the service were asked about the kind of help they would like and how it would need to be delivered if it was to suit their individual circumstances. As a result of the survey, consideration is now being given to ring-fencing part of the home care budget in order to protect and enhance service allocations to people with caring relatives.

A Crossroads Care Attendant Scheme and a voluntary sitting service operate alongside the statutory domiciliary services. Both receive financial support from the local authority and health authority. A recent expansion of the Crossroads Scheme will enable them to provide help to carers of people with mental health problems – a development which was made possible through the Council's bid for funds available from the Mental Health Specific Grant.

To provide relief outside the home for carers, care centres are being established which provide a mixture of day care, short term and long term residential care and a meeting place for carers' support groups. Discussions between centre staff, carers and users have led to a more flexible day service, available until 8.00 pm each day. A pilot care management scheme has also been located in one care centre.

Responsibility for the development of more carer-sensitive services in the Borough rests with a carers development worker, whose post is funded jointly by the health and local authority. The development work is grounded in a philosophy of shared care, where support for carers is seen as an integral part of health and social care provision.

Contacts for further information

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and/or

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Programme Coordinator
Sutton Carers Project

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CARERS' ORGANISATIONS

(15) **East Sussex** was the site of one of three demonstration projects funded by the Department of Health in the mid-1980s to 'enhance and create new services for carers'. This initiative was taken up by the Care for the Carers Council, based in Lewes. Since Department of Health funding ceased in 1989, work on carers' issues has continued to have a high profile in the county, with particular emphasis on policy development in the light of current community care changes.

The local statutory agencies back the Care for the Carers Council in two ways – by grant aiding its work and by offering carer representation on policy-making bodies. A worker from social services is seconded to co-ordinate work carried out in three districts within the county: Eastbourne; Brighton; and Hastings and Rother.

Hastings and Rother carers' development group enjoys the full support of the various statutory agencies, including health services, social services, the Family Health Services Authority, the housing department and education authorities. Regular meetings are held involving these statutory agencies and the carers to review the planning and delivery of services. Carers' issues are raised and identified at local carers' forums and fed through elected representatives on the development group into the joint planning structures.

Contact for further information

Sandy Lazarus
Development Worker
East Sussex Care for the Carers Council
(Hastings and Rother Office)
48 Cambridge Gardens
Hastings
TN34 1EN
Tel: (0424) 717931

USEFUL READING

Policy and research

General

Caring Costs. Taking Care, Making Do: The costs of caring for a disabled person at home. 1991.

Carers' Needs: A 10 point plan for carers. London, King's Fund Centre, 1989.

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Caring in black and minority ethnic communities

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Alzheimer's Disease Society. Caring for the Person with Dementia: A guide for families and other carers (2nd edition). London, 1989.

Birmingham City Council. Community Care and You: Listening to service users. 1991.

CancerLink. Life with Cancer: A guide for people with cancer, their friends and families. London, 1988.

Eribo Dr Lynda. The Support You Need: Information for carers of Afro-Caribbean elderly people. London, King's Fund Centre, 1991.

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Manchester Council for Community Relations. Awaaz: Video and booklet for Asian parents of children with special needs. Manchester, 1990.

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The Open University. Working with Older People. Milton Keynes, 1989.

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Bailey Distribution Limited
Dept KFP
Learoyd Road
Mountfield Industrial Estate
New Romney
Kent
TN28 8XU

For enquiries about prices, please contact the Bookshop at the King's Fund Centre on 071-267 6111.

APPENDIX: CHECKLISTS FOR CARERS

Changes in community care

Many changes will be taking place in community care services during the 1990s. Carers have an opportunity to influence these changes so that they get a better deal for themselves and for the people they care for. For the first time, health and local authorities are being asked to make practical support for carers a high priority.

By asking the right questions, you can find out what they are planning to do to meet carers' needs. Your questions will encourage those who provide services to really listen to what carers are saying they want and need.

Questions you can ask

This leaflet has two lists of questions. The first is aimed at carers' groups – to help you find out what your local council and health authority intend to do to help carers. The second – shorter – checklist is for individual carers and we suggest you use it if you want to get help for yourself and the person you are looking after. The questions are only triggers to help you get started, so do add your own questions! If you are not satisfied with the answers you get, say so, and ask why it is not possible to do things another way.

(1) Checklist for carers' groups

In 1992, your local council will publish its first community care plan, and your district health authority will also have to produce a plan for community care services. Ideally they will produce a joint plan – but this may not happen in every area. These plans will show how community care will be provided for ill or disabled people and their carers.

Carers must be consulted when these plans are drawn up. Carers' organisations can use this checklist to find out what help you can expect from services and how you can get involved in the planning process.

Policy

- Are carers entitled to any help and if so, what and when?
- Will carers' own needs be considered before decisions are made about services to be offered to the people they care for and how is this to be done?

Consultation

- How will the authorities find out what carers and users want and need?
- How are carers and users involved in planning services?

Information

- How can carers find out what different services are available?
- How will information be provided for people who speak languages other than English, and people who have visual, hearing or learning difficulties?

Services

- What sort of practical help and advice will be available to give carers a break from their caring responsibilities?
- What will be done to make sure that any services provided meet the needs of the person needing care and the carer too?

Fair treatment and equal opportunities

- How will services be provided to meet the particular needs of both men and women; different black and minority ethnic groups; and people with different types and levels of disability?

Advocates representing carers' interests

- How will service providers work with people whom carers have asked to speak on their behalf and put their case at assessment interviews and other meetings?

Carers' organisations

- What financial and/or other support is provided for carers' groups and organisations which represent their interests?

Asking for help

- How are staff trained to respond to carers who approach them for help? What can carers expect to happen when they call in or telephone asking for help?
- What arrangements are there to ensure that carers are kept informed of how their request for help is being dealt with?

Assessment

- How do you explain to carers what an assessment is and why it is necessary?
- How will carers and users be able to discuss their own needs and feelings separately and in private as part of the assessment?

Form-filling

- What is being done to ensure that carers and users do not have to fill in more than one form in order to get several different services?

Single point of contact

- Will each carer have the name and telephone number of one person (and their deputy) who is responsible for dealing with them?

Written agreements

- Following an assessment, will there be a written agreement which says what services the carer and user will receive and will it also say which services the authority is currently unable to provide?

Complaints

- What can carers and users do if they are dissatisfied with a service they are receiving or if they disagree with a decision made after their assessment or are told they are not eligible for an assessment?

Monitoring

- How does the authority plan to find out whether the services they provide are of a satisfactory standard and will carers and users be asked for their views?

(2) Checklist for individual carers

Dear Carer

This checklist is for you to use if you want to get help for yourself and for the person you are caring for. The questions are triggers to help you get started so do add your own! If you are already in touch with someone like a home help, social worker or district nurse, ask them these questions.

- Who can I talk to about the difficulties I am having as a carer?
- Where can I get help and should I telephone or call in?
- How can I decide what help to ask for when I am not sure what help is available?
- What will happen when I ask for help?
- How will I know who is dealing with my request and when I can expect to get an answer?
- I understand someone will assess my needs before I get any help. What does this involve and how will they find out what I need?
- If I want to, can I speak in private to the person doing the assessment?
- How long will it take to get the results of the assessment and how will I be told?

- Will there be one person I can turn to who will know about my situation and who will help me?
- Where can I go if I am unhappy with the services that I or the person I am caring for are using?

Am I a carer?

A carer is someone who regularly helps a relative or friend who is disabled or ill with tasks like dressing, shopping or household tasks or who offers other sorts of practical or emotional support.

‘I’m fifteen years old and live with my mum who has multiple sclerosis so before and after school I do most of the cooking and housework. Am I a carer?’
YES.

‘I work full-time as a teacher but also look after my elderly mother who lives with me and who has severe arthritis which means I have to help her with things like bathing and dressing. Am I a carer?’ YES

‘Our fourteen-year-old daughter has severe learning difficulties and can be aggressive which is a problem for our other children; we also have a lot of broken nights. She goes to a special school but otherwise she is at home all the time. Are we carers?’ YES

‘My wife had a stroke five years ago and now I have to do everything for her like feeding, washing and dressing her which means I have had to give up my job as she cannot be left alone. Am I a carer?’ YES

‘My thirty-seven year old son has been in and out of mental hospitals for the last fifteen years; when he comes out of hospital he usually ends up living with me as there is really nowhere else for him to go. Am I a carer?’ YES

Who are carers looking after?

Carers are supporting people with a range of different needs, usually as the result of a long-term illness or disability such as:

- physical disability (e.g. arthritis);
- sensory disability (loss of sight and/or hearing);
- learning difficulties (formerly known as 'mental handicap');
- mental health problems (e.g. Alzheimer's disease);
- long-term illness;
- a combination of any of these.

FOCUS ON CARERS is a practical workbook to help local and health authorities as they implement the NHS and Community Care Act. It lays the foundation on which they can build better practical support for carers in the new community care era.

Developed in consultation with carers, service users and community care agencies, **FOCUS ON CARERS** takes a fresh look at community care planning, needs assessment, and service delivery - all from a carer's perspective.

The practice guidance:

- highlights carers' concerns about community care;
- provides practical tips on action by authorities;
- documents practical initiatives underway in different localities.

Also available

CHECKLISTS FOR CARERS is a companion leaflet to **FOCUS ON CARERS**. It lists questions which carers are asking about new plans and procedures in community care. It can be used to aid discussions between service agencies and carers. Leaflets cost £3.00 per 100 copies.

More copies of this book and the checklists can be obtained from Bailey Distribution Ltd, Mountfield Industrial Estate, Learoyd Road, New Romney, Kent TN28 8XV.

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