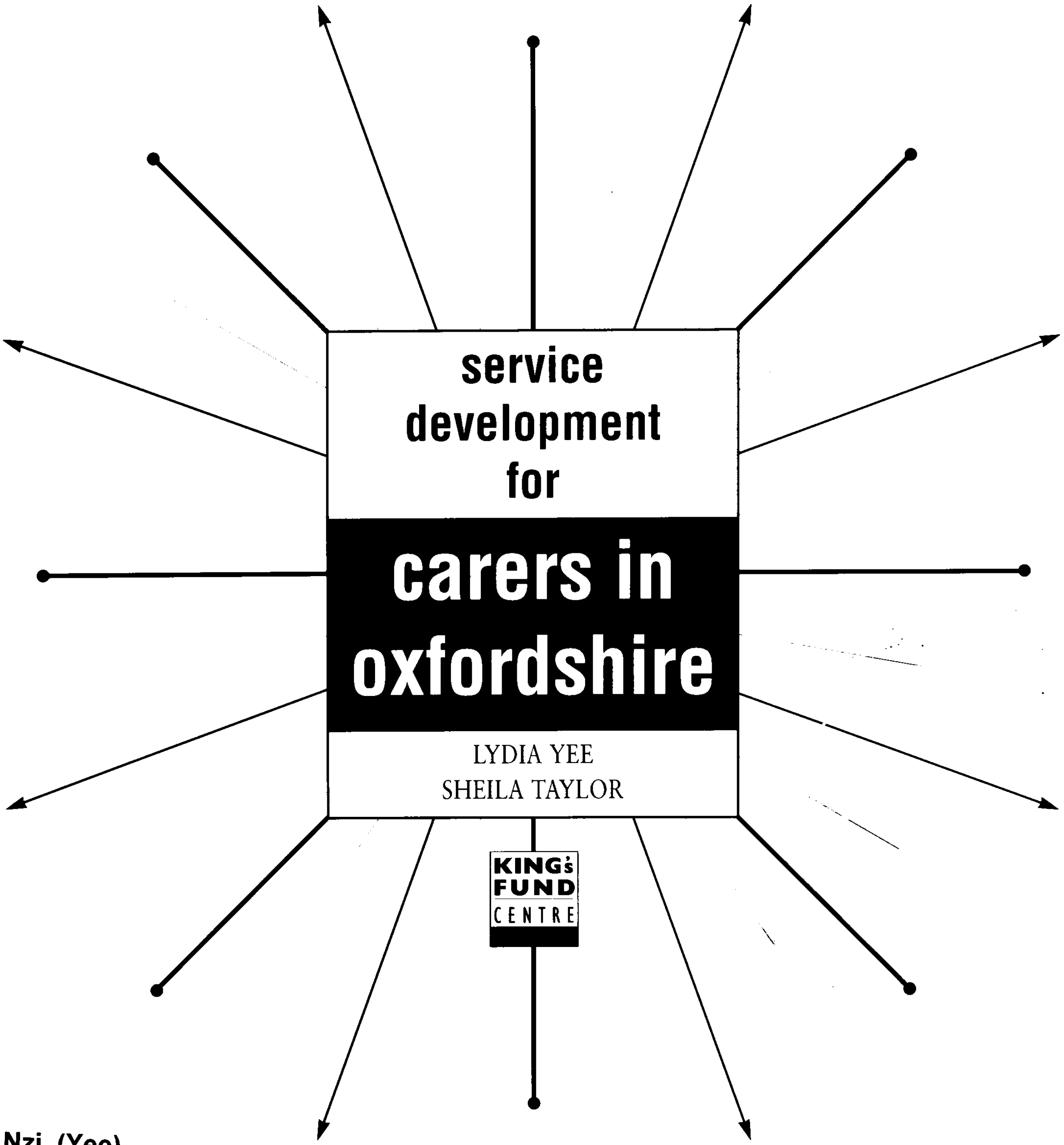

service development for

carers in oxfordshire

LYDIA YEE
SHEILA TAYLOR

KING's FUND CENTRE

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Published by the King's Fund Centre
126 Albert Street
London
NW1 7NF

Tel: 071-267 6111

ISBN 1 85717 077 6

A CIP catalogue record for this book is available from the British Library

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

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preface

The King's Fund Centre has been in the forefront of developments to change the way in which support is offered to carers. In practice, this has meant developing work programmes in different localities around the country to analyse, test and make improvements to the planning and delivery of services for carers.

Oxfordshire County Council Social Services Department was one of the localities working in partnership with the King's Fund Centre over the period 1990–2. Together, they established the Oxfordshire Carers Unit and began the challenge to make professionals sensitive to carers' needs and to facilitate improvements in services for carers.

Goodwill on the part of professionals is a vital ingredient in supporting carers' needs but is in itself insufficient to bring about change. Carers must be able to identify practice and policy outcomes which will be of benefit to them and the people they look after (for instance, building a carers' centre, developing an assessment for carers' needs and the administrative systems and training to back it up.)

In this report, we have attempted to chart both the progress made to date and the factors which can thwart the process, such as social services re-organisation, lack of joint work between agencies (health, voluntary and independent sectors) and competition for funding priorities. Carers' issues have, to date, continued to maintain a high (and growing) profile in Oxfordshire. This is also documented in our report.

We aim this report primarily at local carers and professionals as a tribute to the many people who have played an active part in the work of the Oxfordshire Carers Unit and who continue to place carers' issues high on their agendas. We hope that they will be able to recognise much of the progress documented in this report and will also continue the lively debate on some of the difficulties posed so as to develop a service of which carers will be proud.

Lydia Yee, King's Fund Centre
Sheila Taylor, Oxfordshire County Council

acknowledgements

Many people have contributed to the work of the Oxfordshire Carers Unit and have continued to prioritise carers' support. We would like to give warm thanks to the following:

The Oxfordshire Carers Unit Advisory Group, who worked with us over the two years, identifying key issues for carers and steering the work programme to a successful end. Members of the group included: Angela Avis (Head of Nursing, Community Health Unit), Raymond Elliot (Chair, Carers National Association), Sue Kenrick (Co-ordinator, Flexicare Scheme), Paulette Micklewood (Vice-Chair, Alzheimer's Disease Society), Nicholas Welch (Assistant Director of Social Services, Oxfordshire), Brenda Soper (Oxfordshire FHSA), David Evans (GP), Mrs E Jones (Carer and Member of West Indian Day Centre), Mrs E Meade (Carer and Member of West Indian Day Centre), Mrs P Ayres (Carer).

The Oxfordshire Carers Forum Steering Group: Rev Glyn Evans (Chair), Margaret Coventry, Betty Dickinson, Angie Gardiner, Dennis Ives, Joy Pollock, Aileen Slattery, Ivor Stevenson, Judith Wardle, Mike O'Doughan, Pat Ayres, Ted Crudge, Gillian Gelder, Nita Needham, Julie West, Jenny Slater.

The Oxfordshire Carers Forum, who told us what they expected of the project and supported the continuation of its work programme.

Patricia Southcott and team members for their commitment and enthusiasm towards improving carers' lives.

The 61,000 carers in Oxfordshire, without whom this report would not have been possible.

We also acknowledge the vital contributions and support of the following, without whom the Oxfordshire Carers Unit would not have been established: Ian White (Director, Oxfordshire Social Services) and Janice Robinson (Director, Community Care Group, King's Fund Centre), who provided the funds, encouragement and a starting point.

Roger Morgan and Keith Hawley, from Oxfordshire County Council Social Services Department, who recognised the potential of supporting carers and played a major part in developing the work programme.

Thank you also to Linda Moore and Melanie Kornitzer for typing successive drafts with great patience, and to the King's Fund Centre Publications Unit.

The publication of this report has been financed by Oxfordshire County Council and Gatsby Charitable Foundation. Our thanks to them.

1

SETTING THE CARERS' SCENE IN OXFORDSHIRE

■ Introduction

Oxfordshire County Council Social Services Committee accepted the importance of carers requiring services to assist them with their caring roles through the adoption of the carers' charter (see Appendix 1) in 1989. The Committee had previously agreed to make an addition to the social services policy and budget plans to provide 'relief care in the home', allocating £100,000 in 1987/88 and £150,000 in 1988/89. This lead from above has been a significant feature of service development for carers in Oxfordshire, where the recognition of carers' needs permeated throughout the social services structure, from its politicians and senior managers to practitioners at ground level. This all-party political support of county councillors for the development of carers' services, combined with support from the Director of Social Services, has largely contributed to the national debate on carers' issues.

■ The Carers Unit

A carers unit, working in partnership with the King's Fund Centre, was set up in Oxfordshire in 1990. Its remit was to translate the carers' charter into practical support for carers and monitor the process by:

- working with individual carers to assist them in accessing services;
- working with service providers across all agencies to help them adapt and develop services to support carers;
- reporting any gaps in services and any changes taking place to the senior management of Oxfordshire Social Services Department;
- collecting, collating, disseminating and directing information to carers and professionals;
- enabling organisations to become more responsive to carers' needs;
- establishing a carers' forum to work closely with the Unit and to feed carers' views into the planning and service development policies of the various agencies.

Enabling the social services department to implement the carers' charter provided the focus for the Unit's work and exerted a major influence on its programme.

The approach

There is a wealth of research on carers, and the experiences from pilot schemes are also extensively documented. It was therefore essential that the lessons already learned were used to develop services which would become embedded within the policies and practices of statutory agencies. Similarly, there was evidence of good practice among a number of professional workers across the agencies, and this provided the project with the opportunity of building on their goodwill and experience.

The Unit sought to encourage development and ownership of initiatives at both manager and fieldwork levels within the different agencies operating across the county. The aim was to create momentum and a groundswell of activity on carers' behalf, while at the same time developing a strong and cohesive voice for carers themselves through the development of a carers' forum.

This approach has proved to be successful, in so far as practitioners and middle managers have initiated a range of schemes with senior management support. These are discussed further in Chapter 4.

■ Establishing the work programme

The Carers Unit was based in the Social Services Department, with the latter having responsibility for the project's management overall. An advisory group comprising colleagues from the voluntary sector, health and social services and carers themselves, was convened from the beginning to help oversee the project and steer the two-year programme of work. The advisory group had no management functions and saw its role as advising and guiding.

Based in Yarnton House, part of the Social Services headquarters and located seven miles from Oxford city centre, the Carers Unit identified its work programme as having two distinctive activities:

1. To provide assistance to individual carers, helping them access both health and social services if appropriate, through the telephone advisory line. Information, advice and emotional support were offered to carers, identifying the types of help needed and advocating on their behalf with other agencies.
2. To undertake development work with service providers to ensure that what was provided reflected the needs of carers and offered them support. For instance, a staff reference group from across the districts carried out work to identify services offered to carers and how best to improve them.

Continuous change

Throughout the life of the project, both the local authority and the NHS underwent radical change. Indeed, the Social Services Department within which the Unit was placed had two major reorganisations. The first involved reorganising the work responsibilities of different managers, and the second was to change service provision as required by the NHS and Community Care Act 1990.

During this period of major changes, the Social Services Department and the Unit remained firm in their commitment to the agreed service development agenda. This commitment was reinforced in 1993 with the appointment of the programme co-ordinator to the Social Services Commissioning Team, where she has special responsibility for increasing the involvement of carers in planning services and for developing respite care.

■ Carers as co-workers and 'experts'

Continuous dialogue with carers was one of the main features of the Unit's work and served to ensure that its focus was not diverted by the many changes taking place within the local authority, the NHS and other agencies.

From the start, the Unit operated from the viewpoint that carers were to be influential in how it worked. They were regarded as its 'experts' and co-workers. The team took the view that carers had to be perceived as partners in the provision of community care who, while needing support, were not clients in the traditional sense.

A unique approach

It was intended that the service development aspect of the programme would actually change the way in which mainstream services are provided for carers, to meet the needs of carers as individuals in their own right. Through the telephone advisory service, gaps in the services to support carers would be identified and fed into the development work with service providers.

For the first time in Oxfordshire, an initiative was established to analyse and change mainstream provision of support to carers, accepting that carers rely on local authority and NHS services, as well as on the traditional support of voluntary bodies that have set up projects and schemes using grant monies.

2

THE CARERS' VOICE

When the project started, the co-ordinated voice of carers was virtually non-existent in the county. There were a small number of carers' groups providing mutual support, but little development of a cohesive and organised forum through which carers could express their views.

While professional groups and voluntary organisations were able to meet and lobby for improvements in services, carers had little opportunity to develop their own thinking about the role that they played within the provision of community care and the implications. Oxfordshire carers needed to be able to meet, to debate issues and develop their own views.

Workers in statutory and voluntary organisations throughout Oxfordshire were extremely helpful by using their networks to publicise events, by encouraging carers known to them to join in the Forum's development and by providing practical help with transport, respite care, etc.

Links were made between the advisory service of the Carers Unit and the Forum. Forum members used the advisory service, and carers were given information about the Forum and its aims. This, combined with encouragement and practical support from colleagues and wide use of the media, led to substantial numbers of carers attending the first public meeting and subsequent ones called to discuss establishment of the Carers Forum.

It is often argued that carers are a difficult group to pull together because of their individual situations and pressures upon their time and freedom. However, using a combination of methods, the Forum was established with a substantial membership and now reaches approximately 500 carers through its newsletter. It also regularly broadcasts on radio and television in order to reach those who cannot, or do not wish to, attend meetings.

■ Establishing the Carers Forum

A small steering group of carers, which was formed at the first public meeting, worked relentlessly and at great personal cost to bring the Forum to fruition.

The development of the Carers Forum has had a significant effect on the way in which carers are perceived by agencies, and how they perceive themselves and the role they play.

The arrangements made to enable carers to take part in the Forum provide valuable lessons for agencies who are required to seek both carers' and users' views and involvement. They include:

- the timing of meetings should be given special consideration in order to account for carers' domestic arrangements – lunchtime was found to be the most convenient;
- carers should be given the opportunity to share recent news about their own situations, briefly tell their story and express some of their frustration before going on to the business of the meeting;
- carers should be enabled to gather information or learn about useful contacts or schemes. The Unit never held a carers' meeting without ensuring that the investment of carers' time was recognised and worthwhile. This applied both to steering group meetings to which a senior manager may be invited and to the full Forum meetings. At the latter, the Carers' Advisory Service officers would run a 'clinic' where an information stand may be provided or the meeting was attended by a policy specialist.

As is constantly happening with the raising of the carers' profile, a new issue has emerged in that the county council's own employees with caring responsibilities are finding that they cannot attend daytime meetings of the Forum. A way will need to be found to accommodate the time constraints of not only non-working carers but of those trying to hold down jobs as well.

Compatibility with planning systems and structures

The Carers Forum covers the whole of the county and, while this is useful in terms of relating to county-wide planning systems, it is not entirely ideal for carers living in the five local district council areas which form the county of Oxfordshire. Therefore, as the Forum developed and grew in size, it had to address the issue of how to enable participation of carers at local as well as strategic levels of planning and to ensure that carers were able to attend events and express their views, without having to travel long distances.

Trying to fit carers into complex and apparently ever-changing planning systems and structures, forced upon the Forum a solution which, though not ideal, seems compatible with the decision-making process of the statutory agencies. In order to influence planning decisions from an early stage, the Forum devised a *reference group structure* relating to the five existing client groups and allowing for two more to be established as necessary. Thus, there are carers' reference groups contributing to plans for mental health services, services for people with disabilities, services for older people, etc.

Similarly, by recognising the geographical divisions and district councils, the forum's constitution allowed for the establishment of local fora under its umbrella.

■ Forum management

The growth of the Forum and its impact have meant that carers in Oxfordshire have had to move swiftly from their original position as a loose group of individuals who met occasionally to a new one which involves learning and taking on management responsibilities. Through joint finance and the support of the Princess Royal Trust for Carers, the Carers Forum now employs its own staff – a co-ordinator and an administrative assistant – and, through support from British Telecom, a development worker.

This has been a tremendous shift. Developing a major organisation, obtaining charitable status, taking on employment responsibilities, participating in and making representation to formal committees, developing organisational skills and organising assertiveness training in a very short period of time, are a significant achievement.

■ Demands upon the Forum

Increasingly, carers are being approached for their views and asked to participate. An example is quality assurance related to hospital discharge. Recognition of carers and their voice is something for which many people have been striving. However, the demands on them and on their organisation are considerable. Trying to reach and co-ordinate the voice of a very large group of people (there are an estimated 61,000 carers in Oxfordshire) is no mean task. The Forum staff are kept very busy and their management skills challenged by the co-ordination and administrative functions in themselves, as well as by the need to take up the issues that they present in the most appropriate and effective manner. A further challenge will be to maintain the commitment of existing carers now that the organisation is widely publicised, and to attract new participants. Similarly, maintaining the organisation as 'carer-controlled', when it has to respond to bureaucratic processes and instructions, will demand a constant checking of its own policies and practices.

Without doubt, the Carers Forum has contributed to raising the awareness of carers themselves; their frustration, determination, commitment, increasing confidence and politicisation have brought about a cohesion and strength that many thought impossible.

3

BLACK* CARERS

* We use the term 'Black' to refer to people from racial or other minorities who may be disadvantaged because of their backgrounds.

■ Minimal representation

Apart from the two Black carers on the advisory group, the involvement and representation of Black carers have been minimal throughout the life of the project. The Carers Unit organised information days in a West-Indian day centre, offering an information and advice service, and drawing on the help of colleagues from both the health and social services sectors to give talks on a variety of issues.

With no visible Black carers' group in the county or any Black workers in the team, it has been difficult to reach out to them. It will require a lot of time to engage the trust and confidence of Black carers, who tend not to make use of statutory services because of language and cultural barriers. Since the project ended in 1993, a Black carers' group has been established through the Carers Forum and, more recently, a joint-agency policy development worker has taken up post. This may provide more concentrated and systematic development of services for all Black communities, including carers.

■ What can we learn from this?

There is no single way or one blueprint for getting Black carers together. A variety of methods and processes have to be nurtured and introduced to achieve the involvement of Black carers. The following considerations must be borne in mind.

- In bringing Black carers together, they will need to be clear how they can influence events. Giving up precious time should not only be for support of each other, but also to offer views and to bring about change in service provision.
- Establishing a carers forum is simply not enough to satisfy carer representation. There are the hidden carers, many of whom are Black carers, to pursue and include in its plans.
- Black carers' needs and participation in the work programme cannot be ignored. Service planners should have a strategy and provide resources to suggest how Black carers could be incorporated into the work.
- Full participation of Black carers requires a commitment of resources to provide support with their caring responsibilities so as to enable carers to attend meetings. It should however be recognised that formal committee processes may not be the best way to facilitate carer participation.
- The term *participation of Black carers* needs to be analysed to decide what it means in practice. Is it simply about carers being physically present on a range of committees or rather how they can really effect change to improve the quality of their lives?
- Constructive joint working between carers and workers can be encouraged to bring about changes in attitude, improved and

flexible services and first-hand understanding of the pressures which face both carers and workers. There are examples of this already happening in other parts of Britain, and Oxfordshire could learn from their successes.

4

IMPROVING PRACTICAL SERVICES FOR CARERS

Changing practice and services within the statutory sectors through implementation of the carers' charter was the primary task. The Unit's advisory service was significant in this. Working alongside workers from statutory and voluntary agencies provided a learning experience for those involved. The joint work with professional colleagues engendered through the advocacy and brokerage role, brought about personal and organisational adjustments. Where previously some workers had had a tendency to address the needs of the clients in isolation from the carer, their awareness was raised of the impact of that approach on the carer and other family members. This resulted in a change in their own approach and a recognition of the need for adjustment to services.

■ The Carers' Advisory Service

The Carers' Advisory Service (CAS) played a major role in making professionals more responsive to carers' needs, as well as helping them directly. It had two functions:

1. To provide information, advice, emotional support and a brokerage service to carers.
2. To provide information, advice and support to professionals to help them to improve their work with carers.

Support for carers

Help to carers was provided through

- a helpline;
- interviews in the office;
- an outreach service in the carer's own home.

The aim was to offer a 'one-stop' information service – something repeatedly asked for by carers – and also to enable carers to make choices about their caring roles and what support would be most appropriate.

Carers contacted the CAS direct or were referred by a professional from statutory, voluntary or private organisations.

Philosophy and approach

The carers supported often felt angry, frustrated, guilty, distressed, depressed and, on more than one occasion, had threatened suicide.

The service offered was completely confidential and carers were assured that information would only be shared with other family members or professionals if their permission was given. They were made aware that they would be consulted on any action to be taken. All correspondence and documents were copied to them for their records and all letters written on their behalf were sent to them in draft form for their approval or alteration, unless they advised the service otherwise.

It was made clear that the service was primarily to help carers and would enable them to examine their own needs for practical and/or emotional support if the person for whom they cared was to remain in the community.

Carers were given the time and opportunity for discussion and to disclose the cause of their caring difficulties if it was known. They often found it very difficult to talk about themselves; they felt that sharing information about the person for whom they cared might be regarded as undignified and perceived as betrayal.

They were given support in considering the effect that caring had on their own health, social needs, financial situation and other relationships.

Where carers were distressed, family relationships were considered, including that with the person receiving care, to establish whether that was a contributing factor to their distress. Other factors taken into account included: the level of influence that family members might exert on them; how supportive they were; how they would hinder them in seeking support from any of the caring organisations. For instance, were relatives against carers giving up their caring roles if that were their wish?

In addition, consideration was given to the medical condition of the person for whom they cared. Had the carer been given sufficient information to enable them to consider and understand the diagnosis, prognosis and implications? Who could help support them through a difficult discussion or problem? Similarly, the carer's own health could be a significant factor in their ability to care, and this was carefully explored.

In the case of conflict between carers and the person for whom they cared, carers may acknowledge that they need help and support, but the disabled person may prefer that only the carer should perform the caring role. The service brought the conflict into the open, and both the carer and the person receiving care were given the opportunity to discuss their fears and anxieties regarding their individual perception of the problem. The service provided mediation to enable communication between the parties and help them work towards a compromise solution.

Providing a service for carers entailed investigation into the relationships and working practice of other professionals, establishing whether their assessment had identified the individual carer's situation and needs, and whether these had been taken into account in the care plan. This is an area requiring considerable diplomacy and sensitivity. The service aimed to work alongside professionals to benefit both the carer and the person for whom they cared. Good joint practice led to professionals making increasing use of the information and expertise within the service to help their own approach.

Professionals

Professionals who used and referred to the service were from statutory, voluntary and independent agencies. They became aware of the CAS through joint working, referrals, or as a result of presentations, conferences, seminars and training events.

Professionals and students from across agencies had spent time in the CAS to extend their knowledge of practice with carers.

Tutors within Brookes University, Ruskin College or the College of Further Education have sought information and subsequently been consulted on teaching material for the curriculum.

Social Services Training Section staff within Social Services made regular calls upon the information gathered in the planning of training programmes.

The CAS has met some out-of-county enquiries and requests for research information by holding open days.

■ Continuing support for carers

The introduction of care management with its potential to improve the lot of carers was initially responsible for delaying that improvement. The adjustments being made by workers while still carrying large caseloads operated against their being able to take on board the needs of carers as well as clients. However, as the debate has developed, as the processes have been refined and the involvement of both client and carer in assessments has become more focused, care management appears to have brought greater recognition of carers' own needs, and workers have increasingly called on the Unit and carers' centres for guidance.

The Unit was frequently approached by those whose role it was to seek out major issues around community care and who had some responsibility for trying to resolve them. Thus the Unit was able to influence some of the research and development projects now under way in the county (e.g. respite care being undertaken on behalf of the Regional Health Authority, Oxford).

The voluntary sector played a major role in supporting the Unit, both in responding to requests for help for individuals and in publicising the Unit's work, providing practical help to carers and raising areas of concern.

Relief to carers

Respite care is usually top of the list when carers are asked about the practical support that they need. However, it has been difficult to measure what level of respite care was being provided.

In 1987, the Social Services Committee made funds available to employ 'relief to carers' organisers. Three of the five (now reorganised to three) geographical divisions of the Department subsequently made the appointments and two absorbed the monies into the home care service to deliver the services. The three 'relief to carers' organisers provided support at home to carers. At the time that the Unit opened, one organiser had had a budget increase and was covering all client groups, while the other two provided support for carers of elderly people only. All three had become very committed to supporting carers and strongly advocated on their behalf.

However, the organisers typified many carers' workers: they were very committed to carers but were nevertheless in marginal posts. The care workers that they employed were paid at varying levels, had different conditions of service and were not included in the training programmes of other home care workers. One organiser was soon to be absorbed into the home care service of the division in which she worked and feared that the dedicated budget for carers would disappear.

Through the 'relief to carers' assistants that the organisers employed and through the recruitment of volunteers, carers were able to access direct services specifically designed for them. These services were easily approached and could be measured, unlike those from other areas in the country with no specialist worker and where it has remained difficult to establish what service was being given to carers in their own right. Recording systems within home care had not separated out services for carers from those of clients, and requests by the Unit to participate in the home care managers' training programmes were not met.

Much debate has taken place on the most appropriate method of providing support in the home for carers. One worker with responsibility for carers' services in a large locality can easily become isolated, with other workers passing on all carer issues to him or her. On the other hand, providing services through a home care service facing tremendous demand means that the carer's role can be taken for granted and the whole issue of support for carers can remain unaddressed. Neither situation provides the motivation to increase the range and availability of services for carers themselves.

■ Conclusion

The high profile of carers in Oxfordshire has meant that by 1994:

- in one of the three new divisions, there has been a substantial increase in a budget dedicated specifically to carers, and another worker has been appointed; in another, effort has been concentrated in allocating resources to support carers at home on a population basis, through home care and contracting arrangements with the carers' centre and voluntary sector; finally, in the third division, carer support remains within home care.
- those 'relief to carers' organisers remaining in post have been redesignated 'domiciliary services managers' (the new title for 'home care'), with adjustment to salaries and wages both for them and the care assistants for whom they are responsible.
- assessment and care management systems should eventually ensure that, however structured, services will take into account and record the existence of a carer and the carer's contribution.
- the greater awareness of the impact of caring should result in better support at home.

Much of the work of the Unit, although ultimately aimed at development of services, was centred around creating a climate of understanding and knowledge through which services for carers could be promoted and initiated. The evidence of its work will be in the approaches and range of services introduced and managed by others over time.

5

TRAINING

Influencing training was seen as an important part of being responsive to meeting carers' needs. When the Carers Unit opened, there was very little evidence locally or nationally of staff being trained to work with carers or even to recognise the significant contribution that they made. Professional training emphasised the needs of the client and the carer's contribution was usually taken for granted.

Curriculum design for professional qualification rarely includes how to relate to those caring within a family relationship as opposed to a professional one. This is reflected in debates about confidentiality where carers, who carry the bulk of the caring load, are often not informed of the diagnosis or prognosis of the person for whom they care, which leaves them and the person needing care, in a vulnerable and uncertain position.

Discussion of training had concentrated mainly on training the carers themselves. While acknowledging carers' own requests for guidance on how to care in particular situations (e.g. where nursing tasks are required), the Carers Unit regarded carers themselves as 'experts' and concentrated its efforts on addressing the training needs of professional staff both in awareness and approach.

■ Curriculum advice

Practice knowledge and expertise on carers' issues were reflected in the Unit becoming a member of the Curriculum Advisory Board for the Diploma in Social Work with its membership from the Social Services Department and academic institutions in Oxford.

■ Student placements

The Carers Unit set out to extend the range of current and professional staff who understood carers' issues. Students undertaking the Certificate of Qualification in Social Work (and subsequently the Diploma) in the Oxfordshire colleges spent three-month placements on the Unit. The strategy was to target each educational establishment with a view to developing relationships with the institutions. This would offer opportunities to influence curriculum design and also to create ambassadors among students and tutors. The Unit was a popular placement for students with the schools, and many had to be turned down owing to pressure on Unit staff time. Not only were social work students placed on the Unit, but postgraduate health staff spent time there too.

It was disappointing that the training unit was unable, during this period, to build a staff development strategy incorporating carers' concerns. Training for the implementation of the Children Act and community care arrangements took priority, and it is only now that the training unit is able to address training on users' and carers' issues.

When the Unit opened, it was hoped that the training unit would be at the forefront of moving carers' issues forward. Instead, it proved to be staff at other levels and the training unit was left behind in not meeting many of their needs on this issue.

Early experience of care management has shown that carers are not yet receiving support as required and that practice development needs attention.

As the Carers Unit approaches its planned closure with the development of the three carers' centres which are to replace it, negotiations are under way which address the obvious gaps in training on practice issues with carers within the Department. This is now being addressed. (See page 29 for more details on carers' centres.)

Fortunately, the Unit was in a position to embark upon training as part of its brief. An early report to the Social Services Committee (November 1989) described as part of the Unit's activities, 'to provide training and workshops for front-line staff and middle managers on a multidisciplinary or single professional basis related to methods of working with carers'. This gave the Unit the freedom to develop training initiatives and programmes itself.

6

BEYOND THE KING'S FUND PARTNERSHIP

The county-wide Carers Unit will close in 1994. One part of the strategy has been to establish carers' centres in the three social services divisions (formed in the last reorganisation), thus making support more accessible for carers.

■ Carers' centres

One carers' centre in the north of the county opened in 1992, a second in the south opened in Spring 1994, while the third for the centre of the county and serving Oxford City is currently being developed and operated by staff from the Carers' Unit.

These centres will provide similar functions to the CAS, including: information, advice, advocacy and emotional support to carers. In addition, they will act as catalysts for development. They will have independent status, and carers will play a significant part in their management.

Questions have been posed as to the value of carers' centres. Those in Oxfordshire are being developed as a result of consultations with carers who constantly request the 'one-stop shop' for information. The monitoring of the services provided by such centres has shown that carers value a service 'directly for them'. What is essential is that the centres are proactive in developing networks and linkages between carers and between agencies, and that they continue to develop services. Similarly, it is essential to 'reach out' to carers in isolated communities, particularly in rural areas. As with the Carers Unit, the direct involvement and influence of carers themselves will be paramount to the success of the centres.

■ The future of the Carers Forum

Now firmly established, the Forum will provide a vehicle for the carers' voice in Oxfordshire. It will urge improvements in services to support carers, and those for whom they care, at local and national level.

Carers will continue to co-operate with service planners and press for more appropriate forms of consultation, now recognising that they are playing a major role in the provision of care in the community.

Under the Forum's umbrella, Black carers will be able to present their views in developing support related to their cultural needs.

Support for young carers was the subject of a conference in June 1994 organised by the Carers Forum. This, and the problems encountered by parents of children with special needs – services for whom should be provided through the Children Act – have received less attention than child protection issues, even though there are heavy care responsibilities involved.

Parents' anxieties about the appropriateness and co-ordination of services for young disabled people as they develop into adults remain unanswered. The appointment of a joint agency commissioning officer for learning disabilities in Spring 1994, however, is a first attempt to address this need.

Assessment and care management

Having been monitored, assessment and care management processes developed for April 1993 now need adjustment to recognise and accommodate more effectively carers' own needs. In Spring 1994, the debate was stilll open as to whether carers should have a separate assessment. The Unit, through its advisory service, considered the needs of carers within the context of family relationships. It has been a strong advocate of integrated holistic assessments, with separate assessments being used in circumstances where conflict between carers and those receiving care appears to be a problem. The advisory service, in its practice, has enabled carers and people being cared for to recognise, when in conflict, the issues and to negotiate a solution. This should become part of mainstream practice if recognition is to be given to care provided in a family situation, and this is indeed beginning to happen.

Working carers

Oxfordshire County Council has produced a guide for its own employees who are also carers. It describes the personnel policies and schemes that carers can access to receive support in their employment and caring roles. The initiative followed approaches to the Carers Unit advisory service by the Council's own employees who were experiencing difficulties in combining work and caring responsibilities. Oxfordshire County Council, the county's largest employer, is found to have an age group of workers between 45 and 55 years, 79 per cent of whom are women with 67 per cent of these as part-time workers. These are potential carers for whom the county will have responsibility. The county is beginning to meet this new challenge. A leaflet has recently been published for working carers. It details the County Council's schemes which can accommodate caring responsibilities, such as flexible working hours. The awareness of other employers in the county will be raised at a conference being organised by the County Council.

Respite care

In Oxfordshire, there are a variety of respite schemes, including day care. It is however difficult to establish for whom these are intended, whether client or carer. In fact, such schemes should meet the needs of both (see p.22 on 'Relief to carers'). As assessment and care management processes and recording systems are refined, information about the level of respite care provided for carers *may* become more apparent. The former Carers' Programme Co-ordinator, having been given responsibility for preparation of specifications for respite care within the commissioning team of social services, may help to clarify what respite services are to be provided and their appropriateness both for carers and those they look after. Efforts may be directed at creating more choice and better quality in respite care. The independent sector will have an important part to play alongside the contribution made by the County Council and the NHS.

New ideas are being tried through pilot schemes, such as that in a residential care home where carers themselves, through a relatives' support group, share allocation of carers' respite beds. Where they have proven successful, these schemes are gradually becoming established provision across the county.

Practical support at home

Debate within the county has centred around how this should be provided. One argument is that where a service is provided to support a client, it in turn benefits the carer. The Unit finds this difficult to accept, advocating that the service clearly benefits carers only when assessed as to meet their needs and is provided to them in an appropriate manner.

To move forward on this, a distinction between service to a user and support to a carer has been made by the Unit in consultation with the Forum and a definition of 'support for carers' produced for consideration in the debate.

Carers' service audit

On a number of occasions, gaps in services have been reported. A carers' service audit has also been attempted. Identifying gaps in services in a quantifiable way has proven difficult when services for carers are not clearly identified in the systems of social services departments and others, and differ across the county. More importantly, the management and financial information systems do not provide for data collection. The audit produced subjective information on what was provided on a personal basis by professional and project staff. It has been proposed that systems be adapted to account for services provided to carers. Ultimately, assessment and care management systems should produce data, but this will be subject to the successful implementation of recording and monitoring systems to which staff adhere.

7

THE FUTURE

In Spring 1994, two carers' centres were up and running, and the Unit was about to transfer its current base to provide the remaining centre. The three carers' centres will meet many of the requirements of the carers' charter.

Assessment and care management systems are constantly being refined, with the Carers Forum being consulted as part of the process. Similarly, the Forum is involved at many levels of planning and service development. Its strength lies in the newly organised knowledge and confidence of a large number of carers, and its ability to respond in partnership on issues at local level with the carers' centres. Purchasing and commissioning processes within health and social services recognise and accommodate carers' needs and issues.

The culture has shifted in that carers' issues are, increasingly, reflected in debates, policies and proposals. There remain practice issues to be resolved, particularly with regard to assessment and care management processes, to ensure that the carers' contribution is recognised and respected, and that support for them is planned into care packages through negotiations with them and those for whom they care.

Commitment and support are clearly evident in Oxfordshire to tackle the challenging social care issue of the 1990s – providing real and meaningful support to carers in their own right. (See Appendix 2, an extract from *The Community Care Plan for Oxfordshire 1994–1995/6/7*, for an example of the County Council's commitment to carers' issues.) It has sometimes been difficult to appreciate this, with the internal restructuring being carried out and the changes demanded by community care legislation. There has always been, however, a genuine desire to meet the many agendas of people who are involved with the project and have contributed to its success.

appendix

1

CARERS' NEEDS: A 10-POINT PLAN

Carers need:

1. **Recognition of their contribution** and of their own needs as individuals in their own rights.
2. **Services tailored to their individual circumstances,** needs and views, through discussions at the time help is being planned.
3. **Services which reflect an awareness of differing racial, cultural and religious backgrounds and values,** equally accessible to carers of every race and ethnic origin.
4. **Opportunities for a break,** both for short spells (an afternoon) and for longer periods (a week or more), to relax and have time to themselves.
5. **Practical help** to lighten the tasks of caring, including domestic help, home adaptation, incontinence services and help with transport.
6. **Someone to talk to** about their own emotional needs, at the outset of caring, while they are caring and when the caring task is over.
7. **Information** about available benefits and services as well as how to cope with the particular condition of the person cared for.
8. **An income which covers the costs of caring** and which does not preclude carers taking employment or sharing care with other people.
9. **Opportunities to explore alternatives to family care,** both for the immediate and long-term future.
10. **Services designed through consultation** with carers, at all levels of policy planning.

appendix

2

THE COMMUNITY CARE PLAN FOR OXFORDSHIRE 1994–7: CARERS

This chapter [of the Plan] summarises the policies and priorities that are in place that cover services for carers. Support for carers remains a high priority for the Social Services Department. Developments set out in the client group chapters are summarised here. There are also a range of services that are sometimes of considerable benefit to carers that are part of the general community care developments but not listed here. Day care services are an example of this.

■ Achievements 1993/4

- Premises for the second Carers Centre have been purchased. The Centre will be based in Didcot. Providing information, advice and a focal point for development of support to Carers, it will provide 'Out reach' services in rural areas of South Oxfordshire and the Vale of White Horse. A Manager took up post on 1 February 1994. The Centre is funded through Joint Finance of £80,000 per annum;
- A Drop in Centre for Carers has been established in Witney. Banbury Carers Centre is providing a service to the Centre.

The Carers Unit, based at Yarnton, will continue to function until the third Carers Centre in Oxford City opens in 1994.

- The Social Services Department has designated 12 Carer-controlled Respite care beds in its Elderly Persons Homes (4 in each Division). Carers, through support groups attached to the Homes, will negotiate and allocate use of the beds themselves. Staff are currently developing this service;
- The Abbey at Sutton Courtenay now provides Carers with a weekend away from Caring responsibilities in a restful environment;
- The 'Nightmare to Nightcare' scheme in Oxford City previously funded by the King's Fund Centre for two years is to be continued and funded through the County Council. It supports Carers as well as clients living alone. It is complemented by the Night Nursing service in the City where the two work closely together;
- A contract with an independent Nursing Home has been signed to provide respite care for elderly mentally infirm people. A second Nursing Home is in the process of establishing a similar service;
- A specification for domiciliary care services has been prepared by Social Services which includes the provision of respite care by independent sector providers through domestic or sitting services in the home;
- An agreement has been negotiated with Crossroads Care to provide support to Carers in Bicester and Kidlington;
- Joint Finance of £15,000 has been made available for User and Carer involvement in Community Care Planning. £7,500 a year for three years is being administered by Oxfordshire Carers Forum to cover Carers' travelling and care expenses;

- Oxfordshire County Council has identified personnel policies and schemes which are available to support employees who also have caring responsibilities. It has produced a Leaflet 'Support for Working Carers' describing how these can be accessed and has publicised its existence to all employees.

Consultation

The Oxfordshire Carers Forum was consulted on the following:

- Transport Specification;
- Domiciliary Care Specification;
- The Mental Health Strategy;
- The Joint Elderly Commissioning Strategy;
- Community Care Plan.

It has met with:

- The Social Services Committee;
- Social Services Senior Management Team;
- The General Managers of the Social Services Department, Oxfordshire Health Authority, and Oxfordshire Family Health Services Authority.

■ Priorities and Objectives 1994/97

Support for Carers remains one of the priority areas for the County Council.

Data

The Community Care Plan 1993/94 set out census and other data on carers. Work has been done on further analysis on these data and Table 1 gives information on the numbers of carers in each District and the disability of the person being cared for.

Assessment and Care Management

Monitoring of the assessment and care management system indicates that Carers' needs are not being given adequate attention through the integrated assessment process. Consultations with carers and staff on these processes have taken place and improved systems will be introduced. Performance criteria for carers' support is being developed and further guidance for care managers is being prepared, as well as a specification for staff training. The Community Health Council will be undertaking its own evaluation of assessment and care management during the next 18–20 months, taking particular account of the carers' and users' views of the processes.

Table 1 - Carers providing between 20+ - 100+ Hours of Care per week

Carer Population by Disability of Main Dependant

	Disability of main dependant	Age of main dependant		
		Children <16	Adults 16 - 64	Elderly Adults >65
Cherwell	Physical Disability	41	433	2117
	Mental Disability	19	83	85
	Physical and Mental Disability	45	158	395
	Old Age	0	0	169
	Other	4	14	56
West	Physical Disability	32	338	1649
	Mental Disability	14	64	66
	Physical and Mental Disability	35	123	308
	Old Age	0	0	132
	Other	3	11	44
Cherwell/West Social Services Division	Physical Disability	73	771	3766
	Mental Disability	33	147	151
	Physical and Mental Disability	80	281	703
	Old Age	0	0	301
	Other	7	25	100
Vale	Physical Disability	40	413	2020
	Mental Disability	18	79	81
	Physical and Mental Disability	42	151	377
	Old Age	0	0	162
	Other	4	13	54

Table 1 (cont.)

South	Physical Disability	43	451	2204
	Mental Disability	19	86	88
	Physical and Mental Disability	46	165	412
	Old Age	0	0	176
	Other	5	14	59
Vale and South Social Services Division	Physical Disability	83	864	4224
	Mental Disability	37	165	169
	Physical and Mental Disability	88	316	789
	Old Age	0	0	338
	Other	9	27	113
Oxford City Social Services Division	Physical Disability	39	410	2005
	Mental Disability	18	78	80
	Physical and Mental Disability	42	150	375
	Old Age	0	0	160
	Other	4	13	53
Oxfordshire	Physical Disability	195	2045	9995
	Mental Disability	88	390	400
	Physical and Mental Disability	210	747	1867
	Old Age	0	0	799
	Other	20	65	266

This table shows the estimated number of Carers for each group of disabled people, according to the age of the disabled person, by District Council and Social Services Divisional Areas.

Source: Oxfordshire Social Services Department/OPIS General Household Survey

Consultation and Feedback

Research into the methods and impact of consultations with Users and Carers on community care was undertaken in the Autumn of 1993. The subsequent report emphasised the need for consultation processes to be ongoing and the importance of regular feedback to users and carers. Quality standards for consultation processes will be set.

Locality development will ensure participation of carers in determining local needs and planning to meet them.

Management and financial information

To achieve greater clarity management and financial information systems separating support for Carers from services for Users will be introduced as far as is practicable.

Respite Care

Consultations with the Carers Forum indicate the following needs in relation to provision of Respite Care:

- flexibility and choice;
- within and outside the home;
- for short and long periods;

- on a regular basis and at times of crisis;
- through careful preparation prior to respite care commencing;
- continuity for children through to adulthood.

Particular emphasis will be given to the development and provision of a range of respite care services for all client groups over the next 3 years. For example, Social Services and the Learning Disabilities National Health Service Trust are looking at ways of together improving access to respite care across the county. Respite services for people with a physical disability will also be reviewed jointly.

Needs identified through consultation

- Greater use of volunteer help and befriending;
- Better provision of information on benefits and services;
- Education of employers about needs of Carer employees;
- Attention to the needs of rural Carers including problems of isolation, transport difficulties and time constraints;
- Policy on confidentiality – Mental Health particularly;
- Separate assessment of Carers' needs where requested;
- Across agency training on Carers' needs;
- Crisis line;
- More GP involvement in carers' support.

■ Planned Developments for 1994/5

Respite Care for Elderly Mentally Infirm People

This is a high priority. During 1994/5 it is intended to develop county wide coverage for this group of people through negotiations and contracts with the independent sector.

Day Care

Day Care is given a high priority in the Special Transitional Grant spending plans of the Social Services Department for 1994/5. Day Care is provided for people living alone and also for those who have Carers. Day Care is designed to benefit individual users; however, it can also provide Carers with a break if the programme of care and practical arrangements are appropriate to the needs of both.

Carers Centre – Oxford City

The Centre is to be funded by £86,000 from the Special Transitional Grant in 1994/5. Consultations are being held with Carers and a Steering Group will shortly be formed to bring plans for the Centre into reality.

With the establishment of a Carers Centre in Oxford City there will be three independent sources of information, advice, advocacy and emotional support for Carers across the county. The Centres will also be a catalyst for developments within the areas they serve. All the centres will be contracted to provide these services for carers, and carers should play a large part in influencing how they deliver those services.

Black Carers

Stimulating appropriate developments and achieving easier access to services for people from black and ethnic communities will receive urgent attention. The Carers Forum held a Seminar during 1993 at which carers gave their views on services. This initiative will be build upon to produce tangible outcomes for black carers in 1994/5.

Young Carers

This is an area which needs a careful and sensitive approach.

A Conference is to take place in the summer which will seek to identify key issues and necessary developments, following which a strategy to support Young Carers will begin to be implemented.

Summary of Developments: Carers

Commissioning Officer: Sheila Taylor

Service Change/Development	Cost 1994/95	Cost 1995/96	Start Date	Person Responsible
Oxford City - Carers Centre	£86,000		Autumn 1994	Dave Seal
Elderly Services - Respite/Relief to Carers				
Vale and South Divsion				
Adult Placement Scheme	£10,000			Nigel Parsons
Maintain flexible Carers	£7,000		1st April 1994	Diana Roberts
Extension of Relief to Carers	£35,000			Nigel Parsons
Cherwell/West Divsion				
Kidlington Crossroads	£10,000			Tine Rees
Oxford City Division				
Sitting Service for Carers	£10,000			Maureen Ball
Home Support for EMI (Spires Team)	£30,000			Carol Frost
Mental Health				
Vale and South Divison				
Relief to Carers	£5,000			Paul O'Hare
Development of 12 carers beds in Social Services homes for Elderly People			April 1994	Monitored by Sheila Taylor

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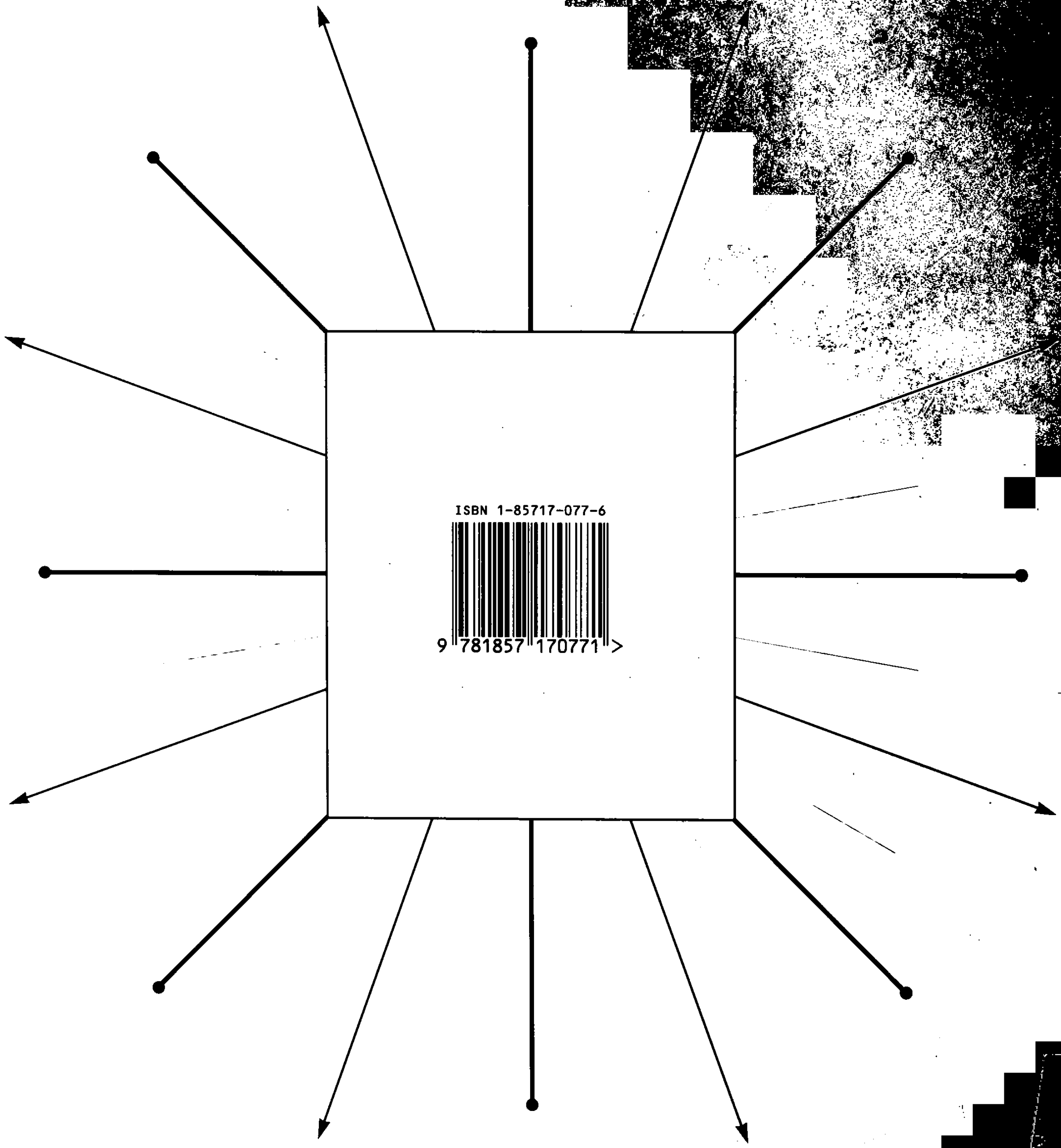

ISBN 1-85717-077-6

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Printed by The College Hill Press Limited (TU), London and Worthing