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BRIDGING THE GAP

Case management and advocacy for people with physical handicaps

Edited by
David J Hunter

King Edward's Hospital Fund for London

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Foreword

The King's Fund Grants Committee considers several hundred applications each year but it can only afford to support about a hundred of these. Often the Committee can only make a contribution to the total cost. This makes it particularly important that we learn clear lessons from the major projects we have been able to fund and try to ensure that the experiences are shared widely. In this way important innovations can be disseminated so that others will also benefit; but equally it can be useful for a project to be described when things do not turn out as planned.

Letting the wider world know of disappointing experiences demands courage, but sharing results on such occasions not only protects scarce resources, but also prevents the unnecessary waste of those essential reservoirs of enthusiasm for service improvement that still abound in the health care and associated fields.

The seminar reported in this book was an innovation for the Grants Committee in that we drew together three projects we had funded which had some similar features. The King's Fund Institute helped with both the background paper and the subsequent analysis and we are grateful for their expert guidance. I hope that readers will find these reports useful, dealing as they do with an important question: How can we ensure that the most vulnerable clients receive all the help they need, and not just a part?

Sir John Batten KCVO MD FRCP
Chairman, King's Fund Grants Committee

Introduction

It is often difficult to understand exactly how innovations come to be accepted within the NHS. Sometimes, fashionable ideas are explored and even widely talked about and yet they never take root. An example of such a fashion a few years ago was the idea that health services needed marketing managers. However, some other ideas seem to have resilience, although it takes the health service a while before it decides exactly how the ideas might become practically implemented; meanwhile, and sometimes over several years, various versions of the general idea are widely explored. It is even more complicated when the innovation is not confined to the health service but also affects social services, housing services and several voluntary bodies, as is the case in some of the projects described in this report.

I believe we should all share the concerns that led to these three important experiments. In general, the concerns can be summarised as an acute awareness that many of the most vulnerable clients, cared for in all our services, do not get the full benefit of all the expertise and practical assistance that could and should be made available to them. This is true whether the clients have suffered head injuries, or are elderly and disabled, or are of any age but disabled from a variety of causes. Each of the projects reported here deals with one of these categories.

In a sense, all three projects recognised that physically disabled people have needs that require completeness in their consideration. Such a holistic approach is difficult to achieve and many professionals, working with devotion and skill, are not able to encompass all the fields within which the disabled deserve help. The disabled, it is too easy to forget, are whole people like the rest of us, with ordinary needs and hopes, which it may be difficult for them to realise; but in addition they have special needs. Far too often, as we know, the individual general practitioner, social worker or therapist has little awareness of the potential in the services that are professionally managed by others. And they may lack the power to mobilise this potential. The projects reported here try in different ways to put together a complete package for clients; they therefore mark an important trend in thinking and caring.

There are some very significant differences between the three projects. In the first report, the Case Management Project puts considerable emphasis on the need for independence of the case managers from the statutory authorities. Those working on the project believe that because they are not employees of any of the statutory authorities they have an objectivity and detachment that is respected by others. In turn this allows the clients' needs to be at the forefront of their minds and they are uninfluenced by resource constraints or local policies that may be inappropriate. The second project is one where the case worker has the experience to know what many patients recovering from head injuries need. In that project it is an expert opinion that is determinant, whereas in the first project a deliberate attempt is made to find out and achieve what the clients themselves think they need. The third project is rather different in that it specifically aims to support, with a new range of skills developed by a multidisciplinary team, those professionals already working in the field. In this model of working, the intention is to help the many professionals and case workers to develop an improved capacity to meet all their clients' needs.

The important thing to remember in all three projects, however, is that there is a general area of difficulty which we need to overcome. Of course, having identified it, the solutions will always be competitive for resources with other opportunities to improve care, and we are not trying in this publication to offer a cost-benefit judgment about the projects that are descibed; that is for others to do.

David Hunter's chapter usefully reviews the many terms that are being used currently to describe the broad idea mentioned above. I think that greater clarity in discussions, and in the analysis of what is being tested in these experiments, may result from the widespread adoption of his terms. I am also very grateful for his historical analysis and for the work he has given to editing this report.

Iden Wickings
Deputy Secretary
King Edward's Hospital Fund for London

PART I
CONTEXT

David J Hunter

Dr David J Hunter is a Health Policy Analyst at the King's Fund Institute. He graduated in political science from the University of Edinburgh where he went on to take his doctorate. He worked in London between 1977 and 1981, first as a research officer at the Outer Circle Policy Unit and then as Health Studies Officer at the Royal Institute of Public Administration. From 1982 until 1987 he was Director, Unit for the Study of the Elderly, Department of Community Medicine, University of Aberdeen. He is the author of several books and numerous articles on health policy, organisation, management, and service delivery in the care of elderly people.

CHAPTER 1

Managed Care: The Problem and the Remedy

'Only connect . . .' (E M Forster)

INTRODUCTION

It is timely to be considering the activities of case managers in the provision of services and support to the priority care groups since it is a subject which receives attention in Sir Roy Griffiths's review of community care (Griffiths, 1988). Many of the organisations submitting evidence to the review, including the National Council for Voluntary Organisations and the King's Fund, placed considerable emphasis on the merits of the case management function. In addition, Sir Roy commissioned a paper on case management from the Public Expenditure Policy Unit. The subject, therefore, is one which has attracted considerable attention over the past year or so.

The aim of this chapter is to provide a general background context against which to consider the three specific examples of case management described in Part II. It is not intended to be a commentary on, or critique of, these initiatives (this is the purpose of the independent evaluations of two of the schemes) although it seeks to address issues and raise questions which may be pertinent to them. The issues explored in this chapter served as the basis for general discussion at the conference (see chapter 5).

In what follows, a number of dimensions of managed care are examined: possible explanations for the recent flurry of interest in concepts like 'coordinator' and 'case manager'; the myriad forms such concepts can take in practice; the relationship between such devices and orthodox service responses; the issue of accountability in regard both to existing services and to users; and the skills and abilities which seem essential to successful coordination or case management and the training and staff development implications of these. There will be other issues – the chapter does not purport to be exhaustive in its coverage – but those considered appear to be among the most important. A final section – in the form of an agenda for discussion – rehearses the main issues covered and raises some wider concerns about case manager roles. These are taken up again in chapter 5.

MODELS OF CASE MANAGEMENT

A clarification of terminology is in order. Case management is something of a portmanteau term which embraces a number of different ways of managing care. It also embraces other concepts like 'coordination' and 'key working' although it goes beyond these activities in its scope and range of responsibilities. Confusion can arise over the generic use of the term case management to cover all attempts to coordinate services or its use in a more specific and technical sense to describe a particular model of managed care. Its use in both senses was evident throughout the discussions on the general theme of case management and its manifestation in the three projects.

Five models of case management were identified at the conference. Three of these were derived from the projects under consideration. The first model emphasises client advocacy with the client taking the initiative and working with a case manager to obtain the services and resources assessed as being necessary to support that individual. The Camden Case Manager Project, in which the case managers are directly accountable to clients, is a good example of this model. The second model of case management is more directive in identifying client needs when, as in the case of the severe head injury study at St Bartholomew's Hospital, clients are unable to articulate their needs owing to a loss of executive function. Third, case management can combine client advocacy with efficient resource use through a system of delegated budgets to individual case managers. The Kent Community Care Project is the best known example of this model in the UK. Fourth, case management may attempt to combine client advocacy on an individual basis with a concern to further the interests of the care group as a whole. Case management in this model directs its attention towards the activities of service managers and planners at senior levels in health and local authorities. The Disability Team in Westminster and Kensington and Chelsea is an example of this model in operation. Finally, there are key workers who are sometimes referred to as case managers or vice versa. While there is overlap in their respective roles, key workers in general have a much narrower role which is service specific. Whereas a client may have several key workers if he or she passes through a range of different services, there will only be one case manager for each client. Moreover while a key worker can be an advocate for the client or his or her family, more often he or she is there to facilitate the coordination and efficient allocation of services.

The definitions of case management offered above to avoid confusion in the subsequent account of the three projects are the product of the deliberations during the discussions of the three schemes. There is, however, no agreed or accepted single definition of case management which holds good across all initiatives going under the term.

BACKGROUND

It is only in the last few years that concepts like 'coordinator', 'case manager' and 'key worker' have entered the social care lexicon in the United Kingdom and assumed a high profile. Cynics might be tempted to conclude that they represent yet another example, albeit a small one, of the growing Americanisation of Britian, and it is undoubtedly true that many of the ideas have been imported from the States. Given that the concept of case manager stems from patchy, piecemeal, fragmented service provision which allows individuals to fall between or through services, it is hardly surprising that the United States has taken the lead in developing these roles. By comparison with the 'non-system' of care in the States, with its profusion of agencies and programs, health and social services in Britain come close to being a model of professional and organisational integration. Nevertheless, it is widely accepted that there are major problems in our system of services for those whose needs do not fall conveniently within the boundaries of a single agency or professional group (and the problems of *interprofessional* joint working *within* agencies are as great if not greater than the problems of *interagency* joint working). A number of reports have documented the problems over the years and many of the issues and ways of tackling them are enshrined in the Disabled Persons (Services, Consultation and Representation) Act 1986, most of which awaits implementation. The major difficulties giving rise to confusion and inefficiency occur between hospital medicine and community health services on the one hand, and between the NHS and local authority and voluntary services on the other hand. Blaxter (1979) describes these in a paper on rehabilitation services produced for the Royal Commission on the NHS and the deficiencies she catalogued nearly a decade ago remain alive.

In perhaps the most far-reaching and well-developed example of case management in Britain – the Kent Community Care Project – Challis and Davies (1986) describe in detail its application to the problems experienced by frail older people. They argue that case management is a response to four interconnected problems: a virtual absence of resource coordination; the difficulty of interweaving statutory and informal care; the relative neglect of older people in social work; and problems of accountability. The Kent Community Care Project is a collaborative venture betweeen Kent Social Services Department and the Personal Social Services Research Unit (PSSRU), University of Kent. Similar schemes, also being evaluated by PSSRU, are operating in Gwynedd, Gateshead, Hammersmith and Cambridge. A brief description of the principles of the project, of the project itself, and of its impact on elderly people is given below.

The community care approach underpinning the project is aimed at providing more effective and efficient support for old people who are at high risk of premature or unnecessary admission to institutions for long-term care. It does so in two ways. First, it provides intensive, skilled and resourceful management of cases. The case managers cement together the fragmented services into packages shaped to individual needs, and reinforce informal support networks, or mobilise resources to create them. Second, it provides a structure which encourages the cost-effective use of resources.

The project has developed mechanisms which make case management possible, and thereby improve the quality of social work intervention with elderly people. To achieve this, social workers have control of a budget which can be used both on services and to develop community support. Several devices have been employed to reduce constraints on fieldworkers' ingenuity. First, their caseloads are relatively small, equivalent to those of workers with vulnerable children, and consist of the most frail elderly, those most likely to require institutional care, and those for whom potential benefits are likely to be greatest. Second, the whole package of social services department provision is nominally costed, both existing services such as day care and scheme developments such as boarding out, all at the level of the individual client. Third, expenditure on individual clients is limited to two-thirds of the cost of a place in a residential home, expenditure beyond that limit requiring line management sanction.

Knowledge of the cost implications of different packages of care is a new element in social workers' decision-making. The expenditure constraint reduces the potential tension for field workers between creativity and accountability by acting as a trigger for management consultation. Assessment of client need becomes problem-oriented rather than constrained by assessment of eligibility for scarce resources. The degree of specialisation in one client group, and the opportunity to tailor more readily resources to individual needs, makes possible more effective working relationships and liaison with other key agencies such as the Health Service.

The original pilot scheme, a collaborative project between the PSSRU and Kent County Council, was undertaken in East Kent, a retirement area where elderly people tended to be more isolated and bereft of support networks than is usually the case. Later developments have occurred in both urban and rural areas. The principles of the scheme permit a wide range of activities to be undertaken, and in practice the use of existing resources plays an important part, carefully interwoven with resources from the local community.

Local people, often neighbours, have been recruited to perform specified tasks for elderly people, usually for relatively small payments as part of an overall package of care. These people range from those with previous caring experience, either professionally or informally in their own families, to those such as the recently widowed or young housewives, with space in their lives which they wish to fill with worthwhile activity.

The Community Care Project has been subjected to careful and rigorous evaluation which suggests that it leads to improvements in both the length and quality of life of clients. The main results are as follows:

halved the probability of death within one year;

halved the probability of admission to long-term care;

doubled the probability of continuing to live at home;

achieved large favourable differences in the probabilities of death, admission to institutions, and remaining at home over three years;

improved surviving clients' own perceptions of their well-being;

improved the quality of their care;

reduced average costs of social services departments without imposing extra costs on the National Health Service;

relieved informal carers of important burdens during clients' lives and reduced costs to them;

reduced the cost to society as a whole of surviving clients.

The model underlying the Community Care Project is transferable to other areas of health care and to other groups besides elderly people. Attempts are being made to extend it to schemes involving the discharge of mentally handicapped and elderly people from hospital, for example, in Maidstone and Darlington.

The Guy's Age Concern Project in London was based on a similar model (Murphy, 1988a). It used a voluntary agency employee as case manager but was targeted at severely disabled dementia sufferers. The case manager had a fixed budget to buy in services from statutory services and to employ local paid helpers and local voluntary agencies. According to Murphy, the scheme proved less successful than the Kent scheme in keeping people out of institutional care. Murphy (1988b) maintains that case managers cannot be held accountable for the quality of service if they have to depend on the voluntary cooperation of other agencies. Similarly, if managers exercise no control over the demand on their service they cannot be held responsible for meeting this demand unless they have an open-ended budget. These two features are among the major differences between the Kent model of case management and that represented by the three projects described in Part II.

However, the projects, like many other innovative projects in community care, remain experimental in character in that they have not so far succeeded in either adapting mainstream services or becoming part of them (Hunter, 1987). Essentially they remain bolt-on accessories to existing provision which continues to pursue a well-trodden, if at times tortuous, path.

Other examples of case management are evident in the DHSS's 'care in the community' initiative launched in 1983 with the aim of providing pump-priming funds over three years to establish innovative pilot projects designed to allow patients currently in long-stay hospitals to be discharged to, and supported more appropriately in, the community. The first steps in the initiative are reported in Renshaw and others (1988). All 28 projects are financed with the proviso that after three years the participating local agencies will take over the cost. Among the projects are a number which display features of coordination and case management. Some, like the Darlington home care project for elderly people, have been documented (Challis and others, 1987; Darlington Health Authority/Durham County Council Social Services Committee, 1987; Stone, 1987).

In the Care of the Elderly People at Home project, a collaborative venture between Gloucester Health Authority and the Open University, the service innovation at the heart of the project is based on the provision of key workers, called care coordinators, attached to three primary health care teams (Carley and others, 1987). There are three aspects to the role: gathering and exchanging information on services and resources available locally that may help older persons remain at home; assessing the individual needs of elderly people who are patients and assisting in meeting those needs; and gathering information for research purposes. The care coordinators work as members of the primary health care teams, receiving referrals from other team members. The needs that the care coordinator tries to meet are agreed with the elderly person and any carers who are involved. On the basis of the agreed needs, the care coordinator will assemble a package of care linking services (statutory, voluntary and informal) to enable the elderly person to stay at home. A checklist will be used by the coordinators to keep a systematic record for monitoring the effectiveness of support.

In its critique of community care policy which triggered the Griffiths review, the Audit Commission (1986) noted, as did the National Audit Office (1987) subsequently in a report on community care, that successful initiatives were often the result of locally integrated services and 'progress chasers' or 'product champions' within them. These displayed features of coordination and case management but also endeavoured to focus activity on 'local' areas which were sufficiently small to allow good relations with professionals to prosper.

A similar point is made by Ferlie and others (1984) who argue that however effective joint working may be at a planning level, it may have little impact at patient level. They recommend the appointment of frontline key workers who would work closely with clients and their families.

> The ability of family key workers to offer individual care packages and to monitor changing needs would help erode the chasm which separates the intentions of higher-tier personnel from the experiences of parents (page 199).

The authors stress the importance of an open referral system in place of a restricted one tied to professionals and of giving greater autonomy to field workers like social workers and community nurses.

Following a more detailed review of services for people with a mental handicap, the Audit Commission (1987) endorsed the need for tailor-made care plans based on an individual case management approach. This was at 'the very centre of effective and efficient care' (page 8). The Commission noted the importance of allowing field staff sufficient autonomy to make decisions if case management was to succeed.

> At the same time, such autonomy must be constrained by the policies of the authority ... and by resource constraints ... A balance must be struck between the often conflicting demands of the individual's needs, the authority's policy and the resources available. A 'loose-tight' arrangement may be suitable requiring a managerial balancing act with considerable autonomy within clear guidelines.

These competing pressures on case management go to the core of what it is intended to achieve. Is it primarily a device to help clients, or providers, or service managers or some combination of these interests? Are they at all compatible or is conflict between them inevitable? We return to these issues repeatedly in the course of the book.

From this skeletal review of the background to case management and coordination in service delivery for the priority care groups in the UK, it is reasonable to conclude that the concepts, while still comparatively novel, are gaining ground and are likely to be given a further push by the Griffiths review of community care. However, as has been noted very briefly, a number of difficulties and ambiguities surround the concepts themselves and many of the developments which they have spawned. The remainder of the chapter attempts to illuminate these in more detail.

MULTIPLE MEANINGS OF CASE MANAGEMENT

Notions of a coordinator or case manager are among the latest additions to the collection of buzzwords that dominate so many health and social policy discussions. As is often the case when new ideas enter into good currency, there is a danger that they are seen as panaceas for particular problems (Mechanic, 1987). Case management in practice varies in scale and scope and also means rather different things to different people in different contexts. In some settings, it may entail reviewing routinely the care needs of a particular group; in others it may involve detailed attention to specific or, to use the jargon, targeted individuals whose cases are especially complex, with the coordinator or case manager involved as a broker in the actual assembly of appropriate services. The three schemes with which the King's Fund has been involved display features of both approaches with a leaning towards a targeted approach.

There are also issues concerning whether notions of case management are primarily about narrow value for money concerns or, as the Audit Commission among others advocates, wider resource efficiency; whether they are chiefly directed towards providing clients/patients with the best and most appropriate care possible; or whether they represent an attempt to do both by balancing these differing requirements.

Although moves to develop case management in America have their origin in cost containment, in practice many involved in their development saw them as potential innovations in care delivery. In the UK there has been a stronger emphasis on coordination, on preventing clients/patients 'falling between stools', and on client advocacy. Only the Kent scheme and its derivatives are explicitly concerned with resource efficiency (as distinct from mere cost containment).

With services being the responsibility of a wide range of overlapping agencies and providers, the case manager is commonly seen as serving as a kind of ombudsman or advocate for the individual. There are possible grounds for conflict here between client/patient advocacy on the one hand and narrow cost containment or rationing considerations on the other. Certainly this has been a sensitive issue in case management in the United States, and North America more generally, which has led to attempts to define more precisely what case management is. For instance, Merrill (1985) suggests that it is not about preadmission screening or utilisation review. Rather, he argues that

> ... case management is a process that is concerned with more than simply monitoring or limiting the volume of services. While cost containment is clearly one objective ..., its prime focus is the organisation and sequence of service and resources to respond to an individual's health care problems.

Nevertheless, as Austin (1983, page 26) points out, if the case management role takes on a resource allocation 'gatekeeping' dimension, 'unmanageable strain' may be caused by asking case managers both to advocate for, and possibly deny services to, their clients.

In a more even-handed vein, Capitman and others (1986) define case management as

> ... an administrative service that directs client movement through a series of phased involvements with the long term care system. It is also an advocacy service that attempts to integrate the formal long term care system with the caregiving provided informally by family members, friends, and community groups.

Turning to the tasks performed by case managers, and acknowledging that case management 'lacks a precise conceptual or operational definition', a National Governors' Association issue brief on case management under Medicaid concluded that

> . . . in the absence of a definition, case management typically describes a range of activities that can vary from routine, minimally professional referral services, to primary nursing, to comprehensive care plan development, oversight, and monitoring.

Austin (1983) and Capitman and others (1986) in a similar exercise go into more detail about the actual tasks of case management. Austin proposes the following list of functions to be included in case management for long-term care:

> screening and determining eligibility;
>
> assessing the need for services and related needs;
>
> care planning (developing a service plan);
>
> requisitioning services;
>
> implementing the service plan, coordinating service delivery, and following up;
>
> reassessing, monitoring and evaluating services periodically.

Such a list, which has much in common with the aims and objectives of the three projects with which this book is concerned, places the emphasis on client/patient needs, with cost containment figuring only to the extent that the most appropriate (that is, efficient) care may be less costly than the alternatives. These different emphases – advocacy and cost containment – need not be in conflict but if they are likely to collide then there are implications for (a) who performs the case manager function, and (b) at what level it is performed.

The lesson to be drawn from the different conceptions of case management noted above is the need to be clear about what it is that case management is intended to achieve since the interests of the various actors involved may well differ. While cost efficiency may be an aim to which all participants might subscribe, the same cannot necessarily be said of cost containment or crude value for money initiatives. For example, from the perspective of government and service managers cost containment might be more prominent in their support for case management than advocating the preferences of individual service recipients. Who the case manager should be therefore becomes an important issue. If the approach is akin to the six functions identified by Austin and listed above, then the case management function probably ought to be left in the hands of an existing service provider or an independent person with particular care skills operating at client level. But if the driving force behind case management is cost control then it is conceivable that the agency involved (for example, a health authority or local authority social services department) will want to control the case management function directly and at a higher level.

Without clarity over purpose, confusion and uncertainty might be the consequence. While this may not be a problem in the context of a few experimental schemes it could well surface as a major issue if case management is adopted more widely. This issue is returned to in the final section.

SOME PROBLEMS WITH CASE MANAGEMENT

Before proceeding further, it is perhaps useful and salutory to return to first principles and cast a sceptical eye over the continual pleas for improved coordination. Like ‘community care’, ‘service coordination’ is an imprecise term and yet equally appealing and seductive in its ability to exude feelings of warmth and human kindness. There is a belief that coordination must intrinsically be ‘a good thing’. But if it is why is there not more of it? And why is there a need to superimpose special coordinating arrangements in order to secure it? It is one of the paradoxes of social policy that calls for better coordination are met with tales of failed attempts to achieve it. As Rein (1983) aptly puts it, coordination is seen as both the problem and the remedy.

Pleas for improved coordination have their origin in four sets of concerns all of which are manifest to some degree in the three case manager projects at the centre of our discussions. First, there is the frontier problem – boundaries and territorial demarcations between professionals, services and agencies militate against coordinated action in respect of care groups whose needs cross sectional divisions. Second, partly arising from the frontier problem, is a perceived overlap and duplication of coverage by services. Third, there is a sense that services which ought to be working together are in fact pulling in different directions and operating at cross-purposes. Finally, it is alleged that an all too evident outcome of a departmental approach to joint working is the appearance of gaps or discontinuities in available services with the result that people 'fall between stools' or 'fall through the net'.

Improved coordination is seen as one, if not *the*, cure to any or all of these deficiencies even if their root causes go much deeper and lie elsewhere. Calls for coordinated care are often based on a number of untested and unproven assumptions about the nature of service delivery. These include the view that frontier problems are organisational in origin; that the necessary skills are present in services with no competence missing; and that every service already operates as effectively as possible within its own boundaries with no allowance made for possible intra-service malfunctions or deficiencies. All that is missing, it is alleged, is proper coordination to meld services together.

Such assumptions can be challenged on a number of grounds. Most important is the fact that improved coordination is no substitute for a certain clarity and agreement over issues. As Rein (page 67) argues, the search for better coordination can camouflage 'the multiple, conflicting hopes that [patients], politicians, administrators and professional service providers and interest groups impose'. Moreover, there are many problems in service delivery which are not problems of coordination *per se* although they may be presented as such. These have to do with the needs of clients which may not neatly fit available services no matter how well coordinated; a shortage of resources; a refusal by an individual to take a service; and professional differences over how a case should be managed which may not be amenable to resolution through the role of a case manager. There are also problems of poor quality services, of inadequate or inappropriate staff skills, of harassed professionals and so on, but none of these is a case management problem.

While it is not the intention to undervalue the benefits of coordination in remedying, or just ameliorating, some of the problems listed above, it would be quite wrong to regard coordination as offering a solution to every organisational and professional boundary problem. Ambiguous legislation, organisational inertia, confused aims, and professional resistance can all influence the extent to which efforts at improved coordination are appropriate and stand some chance of success. In other words, before we become consumed by the prescription, that is, the *machinery* of coordination and the level, or levels, at which it should operate, we need to be fairly sure about the salience or robustness of the diagnosis.

INSIDERS VERSUS OUTSIDERS: CANDIDATES FOR CASE MANAGER

If it is conceded that there is a problem in service coordination at the client/patient-provider interface, the issue arises of whose responsibility it is to tackle it. The three projects with which we were concerned at the conference all rely on independent persons (in terms of both their organisational affiliations and funding) who are, in effect, superimposed onto existing services and arrangements (and this is the case even where these individuals may have worked in the same area but in a different capacity). Such initiatives pose their own particular problems of accountability and of relations with existing providers and users which are considered in the next section. But are there other options or models? Are the tasks being performed by case managers not ones which ought to fall within the domain of particular professional groups, notably GPs, community nurses, home carers and social workers? The reforms contained in the Disabled Persons Act 1986 point in this direction while falling short of any specific mention of managed care. Does the grafting on of new arrangements not reflect a failure of existing services to fulfil their respective remits and does it not serve to postpone or, worse, preempt altogether vigorous attempts to correct these anomalies or management failures? Or, alternatively, are they a sophisticated and necessary adjunct to existing arrangements which, though in theory charged with the task of coordinating care, are in practice incapable of operating to secure it?

In short, are the schemes with which we are concerned merely a pragmatic response to perceived failure in mainstream provision, or do they represent something altogether different and more durable? If the former, then we need to explore the reasons for failure and perhaps seek internal as opposed to external solutions to them. If the latter, then we need to explore the most effective means of ensuring that these external devices can be made more widely available and if necessary made accountable to ensure that they perform in agreed ways. After all, if the caseloads of individual case managers have to be kept low for a variety of obvious reasons given the tasks listed above (see also chapters 2 to 4), what are the practicalities involved in spreading such schemes? Obviously cost considerations enter into the calculus, but even if it can be shown to be the case that savings may accrue from case management there remain questions about the supply of case managers, their requisite skills, and their training and development needs. These issues are addressed in the next section. First, we need to consider whether there is something immutable about the need for external as distinct from internal case managers.

As was mentioned earlier, case management assumes a variety of forms many of which, like the Kent Community Care Project, rely on existing professional groups already in post (in the case of Kent it is social workers) to perform the case management function. What needs to be established is what is unique and different about the three projects that are the focus of attention here – not so much in terms of their own functioning but more in terms of both the model of organisation and funding they represent, and the tasks they purport to be undertaking. Is it conceivable that the tasks of the three projects might be carried out by others who are already part of the service structure locally (for example, GPs, health visitors, social workers)? And, if the answer is yes, why is this not already happening? Finally, if it is thought appropriate for existing providers to be undertaking such tasks, how might they be persuaded to do so: through the example being set by these innovative pilot schemes, by contractual changes, by financial incentives?

In an attempt to address these questions it is necessary to review the duties and experience of those providers who might be expected to perform a case manager role. The groups considered are GPs, health visitors and social workers although there may well be others, notably home carers, equally capable of operating as case managers. Nevertheless, the three groups mentioned would seem to have a particular responsibility or be especially well placed to assume such a role.

General practitioners

Twenty years ago, Richard Titmuss, who had a major influence on the shaping of British social policy in the post-war period, pointed to the dangers of everybody's business becoming nobody's business. Commenting on the role of the general practitioner, Titmuss (1968, page 208) stressed the importance of the generalist. He wrote:

> As I see it, the role of the family doctor is in part ... to help (the patient) humanely to find his way among the complex maze of scientific medicine.

It is widely accepted that for most people seeking help GPs are the gateway to a range of services in the NHS and in the personal social services and voluntary sectors. But research has demonstrated that GPs display very varied responses to the performance of their gatekeeping, or channelling, role. While some see it as an essential component of their work, others find it unimportant and make little attempt to inform themselves of the types and alternative forms of provision which may be available in their localities. There are also those GPs who resent being gatekeepers but who, at the same time, would feel threatened if the role was removed. Even among those GPs who perceive themselves to have a gatekeeping role, many do not regard it as their responsibility to keep a tag on patients if, for instance, they go into hospital for whatever reason. In the view of these GPs, responsibility for those individuals passes to, and rests with, the consultant in charge. GPs will expect to be kept informed of developments but this does not always happen routinely and many instances have been recorded where patients have been transferred to other services or discharged home without the GP having any knowledge of such movements.

GP contracts are usually worded vaguely – for instance, the doctor must 'render all proper and necessary treatment' – which allows individual practitioners a considerable amount of latitude (Pritchard, 1981). There is no code or set of guidelines governing what constitutes proper and necessary treatment and GPs have always resisted any encroachment on their independence.

It would be possible to regard GPs as case managers, as many of them already regard themselves, and to ensure through their training, management responsibilities and contractual obligations that they assumed such a role on a more consistent and explicit basis. There would be a number of advantages in GPs performing this role. Some of these, like GPs being the first point of contact for most people seeking support, have already been mentioned. A further important advantage is the independence of GPs from the services actually delivering care, although tension, if there is tension, between being the patient's advocate on the one hand and a resource manager on the other is not wholly absent (Cantley and Hunter, 1985). Cost control efforts coupled with a growing number of very old people making increasing demands on support systems may be modifying the GP's role from being agent of the patient's welfare to one of balancing the patient's wants and needs against the aggregate population, available services and a limited budget. The role of GPs in such circumstances may be increasingly becoming transformed from *advocating* to *allocating*. There need not be a problem with GPs making these trade-offs unless it is thought that the aim of case management is client/patient advocacy first and foremost.

However, there are a number of arguments against GPs taking on a case management function. Again, some of these have already been mentioned. Perhaps the biggest obstacle is the sheer diversity within general practice where rarely do two GPs, let alone two practices, perform according to the same criteria. In addition, while GPs are expected to have a wide knowledge of medical problems, their knowledge of, or interest in, social problems is decidedly patchy. Moreover, as long as GPs remain independent contractors there are limits to how far it is possible to direct their work particularly towards something as potentially labour-intensive and nebulous as case management. There is evidence that GPs are not always as well-equipped as they might be to deal adequately with the presenting problems of the so-called priority care groups (Hunter and others, 1988).

If GPs are to be encouraged to take on a more explicit and systematic case management role which moves away from the current hit-or-miss situation then it may be that they will require assistance either through the appointment of a practice manager or through the attachment of nurse practitioners. The White Paper on primary health care gives a nod in the direction of supporting such developments. But because many GPs remain distinctly suspicious of, if not outrightly hostile towards, nurse practitioners as well as towards other suggestions to enhance their case management functions, change, if forthcoming at all, will be painfully slow.

Community nurses

Health visitors, district nurses and community psychiatric nurses may be well placed to take on a case management function, particularly when attached to GPs or full members of primary health care teams. Health visitors are specifically entrusted with counselling and advocacy tasks. Many community nurses have extensive knowledge of local neighbourhoods and this trend is likely to grow as the Cumberlege model of neighbourhood nursing takes root encouraged by the DHSS insofar as those localities wishing to adopt such a model may do so. Nurses may also have well-developed relationships with social services and voluntary agencies and be more attuned to social needs than many GPs.

There are, however, a number of obstacles to nurses assuming a case manager role. First, nurses (with the exception usually of health visitors) provide services as well as occasionally offering advice on other services. They may experience difficulty in remaining sufficiently independent to perform an advocacy role. Moreover, they might overplay the importance of nursing care to the possible exclusion of other more appropriate support. It is also the case that health visitors, for example, demonstrate a continuing reluctance to focus their efforts on elderly people or other priority groups, preferring instead to concentrate on their traditional role – that is, attending to children under five and their mothers. Bowling (1981) found that many district nurses did not want to acquire additional skills which might have equipped them to take on case management responsibilities. It is also the Health Visitors' Association's firm policy that under no circumstance should health visitors accept appointment as 'key workers'. Finally, links between community nurses and GPs, even when practice-based, are often fragile and instances have been recorded where nurses are denied access to information that would be deemed essential if they were to function as case managers. As Pritchard (1981, page 34) observes, 'attachment is a device for involving nurses in primary health care, but by itself it achieves very little. It makes team working possible but not inevitable.'

Social workers

Social workers are often regarded as natural case managers even if they do not always see themselves as such. In some places, like Kent, many of them explicitly function in this way. Social workers are charged with tasks of assessment, counselling, advocacy and coordination, which are central to the performance of case management. They are expected to possess a wide knowledge of available services and to steer individuals accordingly. In some places, social workers are attached to GPs although like nurses they may suffer from poor communication, inadequate information-sharing and other more structural differences which render the relationship problematic (Huntington, 1981). In the Barclay report on social workers' role and tasks, little mention is made of case management or key worker responsibilities which some observers regard as a missed opportunity (National Institute for Social Work, 1982).

Possibly the chief difficulty confronting social workers in assuming a responsibility for case management is the sheer scale and diversity of their obligations, many of them of a statutory nature. Historically, social workers have tended to concentrate on child care, and work with the priority care groups such as elderly people has assumed a lower priority and is far less codified. As mentioned earlier, this was one of the factors behind the introduction of case management into Kent Social Services Department. By all accounts, the Kent scheme and its counterparts elsewhere have been successful and there may be scope for extending the approach to other areas. However, a major limitation, if not weakness, of the social services model is its exclusion of health services. Finally, social services departments have displayed a notable reluctance to undertake a more extensive case management/advocacy role as delineated in the Disabled Persons Act 1986 without new resources to cope with the additional demands to flow from such a development. The Act which reached the Statute book was diluted as the Bill passed through Parliament, particularly in regard to the definition of the advocacy role and the recognition of disabled people's representatives. Nevertheless, it marks an advance on previous practice although the opportunities it affords largely remain to be grasped.

As noted earlier, there are other service options which might be considered appropriate for a case management role. In particular, home helps (or home carers in this context) are beginning to apply case management principles in some social services departments (DHSS/Social Services Inspectorate, 1987). There are also possibilities for bodies like voluntary agencies and community health councils to assume some of the tasks outlined above although they are not equipped with the skills to perform assessment or monitoring tasks.

It was pointed out earlier that a major obstacle to encouraging existing service providers to perform a case manager function was the conflict of interest that might result if providers belonged to a service which was itself the cause of problems for clients/patients. Any pretence at independence in such circumstances would be virtually impossible. A possible way out of the dilemma, however, might be to allow service providers in one locality to be advocates for another. They could be permitted to cross agency boundaries so that the employers were different. Alternatively, health services could advocate for social services and vice versa. While a number of logistical problems would need to be overcome, these possibilities have the merit of resolving the tension between advocacy on the one hand and cost containment or resource management on the other hand in favour of the former and in favour of listening to what is wanted by clients/patients rather than simply doing what is seen as best.

ACCOUNTABILITY AND ABILITY

Issues of accountability and ability arise in regard to case manager roles. Accountability is probably less of an issue when the case management role is performed by an existing service as distinct from one expressly established for the purpose. When an independent case manager is appointed there are issues about where and how that individual fits into the organisational and managerial arrangements and to whom he or she is accountable. Is it sufficient for the case manager to be accountable to individual clients/patients or their representatives or guardians? Or do they need to be seen as belonging to the service system in some way?

Regardless of who performs the case manager role – whether through a form of 'insider dealing' or by an outsider – a host of issues arises concerning the requisite skills and abilities which will help enable successful links to be established with patients/clients, their carers and a range of services both statutory and voluntary. It is often asserted that problems of improved coordination between services, and between them and users, are structural in origin and can only be resolved through such means – that the necessary skills to ensure coordinated approaches already exist and merely require the requisite structural forum in order to prosper. However, it is not sufficient to assume that these skills are in some sense automatically present, although the effect of such a prevailing assumption has been a virtual neglect of the roles, skills and training required to make a reality of coordinated care and effective case management. There is an argument that case manager roles ought not to be conceived as simply an extension of existing professional roles since this would be to negate much of their uniqueness and importance. It is necessary to consider the skills and abilities which are required and to determine whether these are compatible with the roles and skills of existing service providers or whether they demand a degree of independence in order for their potential to be fully realised.

A useful notion in attempting to understand the requisite roles and skills is 'reticulist activity' (Friend and others, 1974). A reticulist is a networker or broker, someone who endeavours to blur organisational and professional boundaries by creating and nurturing links between organisations and professionals, and by linking together the 'right' people on the 'right' problems (Schon, 1971). A reticulist must appreciate when to bargain, when to seek to persuade, and when to seek to confront in situations ranging from those where there is a high degree of consensus to those where there is inherent conflict between the interested parties. Typically operating on the margins, or in the interstices, of organisations, reticulists have been referred to as 'responsible schemers' in the successful creation and maintenance of joint working or coordinated networks (Friend, 1983). Reticulist activity and case manager roles have much in common. Yet we know little about the operation of such liaison roles and, in particular, the *processes* underpinning their performance.

In two studies of liaison or coordinating work in respect of older people (Hutchinson and others, 1984; McKeganey and Hunter, 1986), which shared many of the tasks and approaches of the three projects considered here, those involved were well aware of the complexities confronting them and, in one of the studies, described themselves as 'walking a tightrope' between competing and often conflicting claims. In both settings, the work was a combination of clinical medicine (in terms of assessment and monitoring responsibilities) and practical administration involving a considerable degree of personal contact and cooperation with patients/clients, their families and with staff at all levels in the health and social services. A combination of diplomacy and decisiveness was called for in managing and sustaining the networks. Those undertaking the coordinating work in the two studies were existing NHS employees and had clinical training of some sort. However, they were not direct providers of services, although they possessed detailed knowledge of these.

In the context of trying to derive lessons for policy and organisational learning from the three case manager projects, it may be worth applying to them the messages which were derived from the two studies of coordinated joint working mentioned above. These centre on the potential of replicating the approaches in other areas, the skills which seem important for success, and the limits to coordination in situations where the root problems have other more deep-seated causes. Indeed, this last issue is so important that it is developed further in the final section of the chapter.

First, common solutions to common problems probably do not exist. Both the studies referred to, and also the three projects, were products of their respective environments – they were 'bottom-up' rather than 'top-down' responses to perceived problems in each locality. What may work in one locale may be less successful, or even fail, if transferred and imposed elsewhere without adaptation to fit local circumstances. While it is possible, indeed essential, to learn from successful initiatives, any mechanism must be custom-built for the particular environment in which it is to operate.

Second, there needs to be an identified purpose for which some kind of coordinated response is seen to be appropriate. Allied to this requirement, there needs to be agreement on both the nature of the problem and the response to it before joint working or case management can hope to succeed.

Third, in joint activity of the kind described in the two studies, the work is sensitive and political and requires particular skills for its successful execution. The skills are not principally technical or clinical (although they may provide legitimacy and will be required to some extent if assessment and monitoring figure prominently) but social and interpersonal. In the studies mentioned, the clinical background of the coordinators appeared crucial for the effective operation of the initiatives particularly in those situations where negotiations with hospital clinicians were necessary. This is not to suggest that only clinical skills are appropriate or acceptable but there is an issue concerning the professional base from which a case manager comes and the type of training and development, if any, which might be offered. Case managers need to command the respect of service providers if they are to operate successfully.

Fourth, a degree of independence from the services being coordinated seems essential. In the two studies, the absence of 'axes to grind' enabled members to appear reasonably detached and unbiased. At the same time, complete neutrality and detachment would probably have lessened the effectiveness of the initiatives featured in the studies. Some leverage or stake in the system was essential. The tightrope metaphor is apt since success flowed from a tricky combination of coalition building and the formation of a loose alliance with certain provider groups while simultaneously maintaining a degree of independence from all interested parties. The coordinators had no budgets of their own to put together packages of support individually tailored to the needs of the clients/patients so their ability to exert influence had to be sought in other ways – for example, by relieving pressure on a particular service perhaps by offering a more appropriate alternative which was also in keeping with the individual client/patient's wishes. Such trade-offs, balancing acts and deals were the hard currency in which business was conducted.

Fifth, successful coordinator/joint working arrangements are those for which service providers perceive a need. The arrangement featured in the two studies survived because service providers were of the opinion that their activities merited support. They felt helped and supported by the existence of the initiatives in overall terms if not on every occasion. Even in those situations where patient/client advocacy may be uppermost, unless the support of service providers is forthcoming it seems improbable that case manager schemes could survive for long without being marginalised and ultimately rendered redundant.

Finally, case manager schemes cannot be expected to compensate for basic resource shortages or for services under intense pressure. Solutions to such fundamental structural problems surely lie elsewhere. It is all too easy to invoke improved coordination as the cure for a whole range of such problems thereby diverting attention away from what in fact needs to be done. This point is taken up again in the next section.

AN AGENDA FOR DISCUSSION

Having established in preceding sections that there is a genuine problem of coordination to which a case manager approach offers a legitimate response, it remains to recap on the central issues with which the greater part of this chapter has been concerned and which are referred to in subsequent chapters. There are six which have been singled out for comment.

1 Case management may operate in two ways: *either* at the level of practice as a means of securing a holistic view of client/patient needs, of matching these to available resources (which may or may not be controlled by the case manager), and of representing these in an advocacy mode; *or* at higher levels of intervention as a primary management strategy to cope with resource pressures – to do more with less perhaps. Yet, if the root problem is service shortage rather than gaps or duplication what impact can street-level case managers successfully make? Is there a symbolic dimension to such activity in these circumstances with only a faint prospect of practical gain – that is, more effective coordination may release resources to devote to service delivery? Is there a need for case management at different levels or would this be a recipe for conflict?

2 Allied to pleas for case management for the reasons identified earlier, under the rubric of coordination a variety of outcomes is claimed to flow from it: increased efficiency, accessibility, accountability, advocacy, comprehensiveness and participation, to name a few. These are all worthy goals but they are not the same, and different objectives may imply contradictory courses of action in a given instance. For example, case management to eliminate service overlap in no way guarantees improvement in comprehensiveness of services. To the extent that case management attempts to accomplish inconsistent tasks, the reformers may themselves 'fall between stools' and fail to achieve any of them. There is a need, therefore, for some consensus and clarity about what it is that the initiative is intended to achieve and at what level. This, of course, is far easier to state than to accomplish for reasons arising from the complex settings into which case manager roles are introduced. Nevertheless, some notion of what it is that is to be coordinated – people, facilities, policies, resources, information – and at what level – street, local, national – would seem to be a minimum prerequisite.

3 Given the micropolitical milieu in which case management operates, what skills are required by those who occupy these roles, and what incentives might be introduced to assist care managers in their work or to encourage existing service providers to coordinate without the intervention of a third force? Possible incentives might include increased funding, information, additional expertise. If service providers believe that improved coordination will make it easier rather than harder to carry out their work then they are more likely to cooperate and less likely to feel threatened. After all, coordinated or managed care, especially if performed by 'outsiders', usually involves the surrender of some of the resources, power, or autonomy enjoyed by service providers. How best to handle these political issues, and the skills required to do so, demand attention if case management is to succeed. In this context, the insider-outsider issue needs to be addressed. Is case management more likely to succeed if performed by existing staff (for example, GPs, nurses, social workers) modifying their remits or contracts if necessary, or is there merit in employing independent outsiders to perform the work? Different issues arise in each case but all issues need to be worked through before reaching a verdict. It may be that the solutions will vary from place to place depending on the particular political and organisational context.

4 Notwithstanding the encouraging evidence from the Kent Community Care Project and its derivatives, the sense of the literature is that few coordination projects have made an important contribution to client wellbeing even though demonstrating this is difficult. Indeed, Mechanic (1987) points to a number of concerns which need to be successfully resolved if case management is to survive as a viable concept. For instance, assuming a continuing responsibility for clients who are disabled or experience learning difficulties is a role which few professionals other than doctors have undertaken. Second, given the complex and diverse functions which case managers are expected to take on, perhaps specialisation offers greater hope of an effective service.

Third, case management is often a longitudinal process but, certainly in the United States, the attrition rate among case managers is high. Fourth, to be effective case management needs to form an integral part of an organisational plan which defines clearly who is responsible and accountable for the care of patients/clients. Finally, even if successful at the client level, there remains the problem of coordinated care systems at higher levels where success may be more difficult to achieve although just as necessary. In addition, the two levels are interrelated and success (or failure) at one will have implications for the other. Indeed Austin (1983) believes that case management can, and should, become a powerful strategy for altering provider behaviour and for shaping delivery systems. However, the dominant focus of case management is on client-centred activities.

5 The three projects which form the basis of this book are funded for between two and three years. If successful – however success is defined and from whose perspective – there remains the issue of how innovative schemes can become part of mainstream provision. Is there a case for making the allocation of pump-priming funds conditional upon a commitment from some agency to take over funding of a project if, upon evaluation, it is shown to be successful?

6 Some case managers, like the social workers in the Kent Project, have control of a budget which provides an incentive for improved client assessment and makes possible more creative responses to the individual needs of older people and their carers. What are the implications of *not* having a budget? What means are then available to case managers to influence support systems?

The thrust of this agenda for discussion (see chapter 5) may seem pessimistic and unduly negative. It is not intended to be; rather, it is aimed at stimulating, if not provoking, discussion of a policy/management instrument of major, and growing, interest. But we rightly need to be cautious, even sceptical, about advocating case management as a universal solution to problems arising from professional practice and service delivery. There is a risk of 'frontloading' so that managed care becomes a catch all for numerous and competing tasks which even the 'loose-tight' approach favoured by the Audit Commission may be unable to prevent from flying apart. As Mechanic (1987, page 221) warns,

> . . . while the concept of the case manager has intuitive appeal, it remains unclear whether it is appropriate or realistic to assign such varied and complex functions to individuals in contrast to more complex teams or subsystems of care.

Reforming services and addressing the problems to which case management is seen as a response can take many forms. Case management may be a useful, if limited, remedy but it is not the only one available even if it is currently in high fashion. We need to acknowledge its limits as well as its undoubted potential.

PART II
PROJECT DESCRIPTIONS

Case Manager Project, Camden

An application was received at the King's Fund Grants Committee meeting held on 28 November 1985 to fund a two-year pilot project in consumer-directed counselling, planning and advocacy for people with physical disabilities, at a cost of £86,000.

A grant of £46,000 was made to meet the first-year costs of the project. Provided that the first twelve months' experience demonstrated the desirability of the project, the Committee was prepared to fund the second year if no alternative sources of funding could be found and an additional grant of £40,000 was set aside for this purpose. The Committee received a satisfactory progress report at its meeting on 19 November 1986 and released the grant of £40,000 for the second year of the project.

Alistair Anderson, Project Manager, originally worked in a bank and then trained as a social worker based at a community home for delinquent adolescents in Kent and in the Spinal Injuries Unit at the Royal National Orthopaedic Hospital, Stanmore.

Susan Scott-Parker, Project Adviser, worked as a case manager in Canada and became adviser to the Project while working at the City University.

Penny Banks, Case Manager, worked as a social worker in Camden and also in the Spinal Injuries Unit at the Royal National Orthopaedic Hospital, Stanmore.

Vivien Kerr, Administrator, held the post of Voluntary Services Organiser at the Royal National Orthopaedic Hospital, Stanmore.

Doria Pilling, Project Evaluator, is a Research Fellow at City University who undertook an evaluation of the Case Manager Project during its second year.

CHAPTER 2

Case Manager Project, Camden

INTRODUCTION (AA)

When the Spinal Injuries Unit at the Royal National Orthopaedic Hospital in London opened in 1983 one of us was appointed as the Senior Social Worker – at the time the only social worker working full time in such a unit in the United Kingdom. A major task was to help spinally injured patients manage the transition from hospital to community after a traumatically acquired disability. Looking around for a model upon which to base this work, it was apparent that no such model existed in the UK, although one did in the United States. In 1984, together with a physiotherapist and occupational therapist from Stanmore, one of us undertook a five and a half week visit to the United States. While visiting a number of rehabilitation units the role of the case manager was studied. The role contained much of value for practice in the UK with its emphasis on the right of people with disabilities to have a voice and to have a wide range of options which were chosen, not obligatory and not imposed.

With two years funding from the King's Fund, the Case Manager Project was born in January 1986 to explore this method of providing a direct service to people with a physical disability.

The aims of the project were as follows:

- to identify the wishes of the client;
- to plan goals with the client;
- to make better use of resources for clients and service providers;
- to monitor progress of the plan;

to identify gaps and feed these back to policy makers;

to act as a resource to professionals;

to act as an advocate for the client;

to identify and document good practice to provide guidelines for effective coordination of community services;

to work with the evaluation team so that input reflected the research done.

In the early days, policies and procedures were developed using the views of the evaluation planner (see below) and a steering group. After much internal discussion the goals and outcomes of a case manager were defined.

We spent five months 'walking the patch' – getting to know the area and the professionals in it before taking any referrals. We advertised the service via leaflets and printed articles in the local press and disability publications.

THE CASE MANAGER CONCEPT (SS-P)

My involvement as an adviser to the case management project came about when the director discovered that I had been employed and trained as a case manager in Canada. Case management is not new. It has been established in North America for some time as a distinct discipline with a coherent theory and an accepted set of professional practices. Indeed examples of excellence now coming out of North America regarding the way in which service system planning should happen actually include a mix of case management and brokerage services as prerequisites if services are to be genuinely centred on the needs of the client. The extensive literature regarding theory, methodology and standards in the area is readily available. From the beginning, my contact with the project convinced me that case management had a great deal to offer in the British context. The project's considerable success achieved in such a short time has more than confirmed that view.

I was therefore reluctant to speak. In the seven years I have lived and worked here I have discovered that if I want to promote enthusiasm for an idea, the last thing I should do is to say anything about it being developed abroad, particularly in North America and especially in a Canadian accent. But it seemed important in a discussion like this one to remind ourselves that we neither have the time nor the resources to reinvent wheels. We are professionally obligated to learn everything we can about case management theory and practice. Although the systems and cultures differ in the UK from North America, in many ways the goals and values which case management so effectively promotes are the very same goals and values which we would want to see reflected in services here.

Case management provides a basic framework, a tool kit if you like, which can be used in very different systems when the desired outcome, in terms of the quality of service received by people with disabilities, is the same. In my experience those outcomes are not in conflict. For example, we would all hope that the services provided are flexible, client-centred and tailored to the needs of the individual. This means much more than filling in gaps between services. For example: we want individually designed packages of services which enable clients to achieve goals which the clients have set for themselves; clients should be able to choose realistic goals based on accurate and comprehensive information regarding themselves, their disabilities, the services and the community; people should be able to call on expert representatives or advocates who relate or are accountable directly to them and who help them to understand and to control the services they require; and we believe services should be efficiently coordinated, carefully targeted to those clients who most need them and that service plans should be reviewed and changed if necessary. Case management and the integrated set of services it provides makes it easier to achieve these outcomes no matter which system or culture it operates in.

So far I have said very little about coordination. Indeed I am convinced that the term 'coordination' is beginning to create problems in itself. Case management is not coordination; it includes coordination but is not synonymous with it. People with disabilities do not automatically get the benefits of case management when they get coordination; nor does 'coordination' necessarily ensure a more client-centred, goal-oriented or equitable system of service. Indeed 'coordination' is sometimes used to sustain a prescriptive model whereby people with disabilities are told what they need, told what services they should get, and then the resulting package is coordinated, albeit efficiently.

Focusing the debate narrowly on the coordinator's role can distract attention from some of the more fundamental issues. Lack of coordination is merely a symptom of the existence of more basic problems. The real question is how should coordination of services be integrated into a rigorous framework for developing and delivering truly client-centred services? Case management can provide just such a framework. But, and there must be lots of 'buts' flying through everyone's minds, surely we already have numerous professionals and workers who already assume a case manager's role or at least part of it? Surely someone should be doing it if they are just doing their jobs properly? Surely we do not need what would seem to be yet another layer added to an extremely complex system?

I would answer 'yes'. Some professionals are doing it some of the time, for some people, in some places, to varying standards, but we would not be here if it was working or if it could be made to work with some 'rejigging'. Case management is not a part-time job – it cannot be grafted onto someone else's job description. It offers the client a logical step-by-step progression through distinct stages of a complex service, steps which, through necessity, are interlinked. It defeats the purpose to chop it up and ask people whose primary jobs are very different and whose training is very different to try to deliver bits and pieces of it. All sorts of problems develop. For example, professionals and workers attempting to do this find they are unable usefully to mediate between services or work across agency boundaries, an essential part of case management, simply because they are themselves part of those very services. They also confront the difficulties created when they attempt to reconcile their role as gatekeeper with that of the case manager's obligation to represent and advocate on behalf of the client. But the point remains that numerous workers and professionals are attempting to do the jobs they are meant to do, to meet their primary obligations, while at the same time offering fragments of coordination and/or 'case management' services because the need is so great and committed people believe it is better to do something than nothing at all. But time and again we see that it is just not good enough.

It should be possible to rationalise the current system in such a way that case management fits into it, not as a new layer, not even as a third force, but as the missing piece of the jigsaw. We would then free workers and professionals to concentrate on providing the services that they are meant to provide and ensure the development of more efficient, more empowering, and ultimately more cost effective, services as a result.

METHOD OF WORK (PB)

The method of work is based on:

holistic assessment;

plan of action;

coordination of services – case conference;

representation;

checking and monitoring.

The method developed has several critical components all of which are necessary to ensure effective coordination of services and a truly consumer-oriented service. Each stage flows naturally from one to another.

First, in response to a referral when we have ensured the client wishes to see us, we visit aiming to carry out a *holistic assessment.* Such an assessment is fundamental in ensuring that the appropriate services are approached and drawn together with the client. Other professionals may be brought in – for example, from the medical side, physiotherapy, housing and so on – in order to assemble a comprehensive assessment.

The next stage is *a plan of action* worked out with the client and based upon the holistic assessment. This is not a medical model where tasks are set by a team but is more of a contract worked out between the client and case manager. Without this agreement no kind of effective coordination, from the client's point of view, can take place.

Working to this plan the case manager aims to get the necessary *coordinated resources* to the client which may involve providing information on where to go, how the system works, or arranging services on the client's behalf. Where a whole package of services and care needs to be provided the case manager may need to call a case conference to establish with both the client and the services who does what.

As a tool of coordination, case conferences can be vital. But they do need to be used expertly so that they are productive, with a proper focus, with the appropriate agencies asked to attend, minutes taken and a follow up to ensure plans are put into action. Even more essential, the client needs to be the focus. We have found our independence and our method of working directly with the client essential at many case conferences. The client has sometimes felt his voice has not been heard clearly and has valued the support of the case manager and the way in which the agenda is set primarily according to his viewpoint and needs. The case manager has also been able to act as a mediator between different services who have felt unable to step outside their guidelines and precedents. An independent voice at the meeting has often resolved previous impasses, and services have been very willing to respond to an agency working directly with the client and not another service in possible competition for resources.

Thus the role of *advocate and representative* is crucial to our work and to the effectiveness of the coordination of services for the client. Indeed, the Disabled Persons (Services, Consultation and Representation) Act 1986 acknowledges this vital role.

The time-consuming nature of this kind of coordination, where meetings have to be arranged, minutes sent out and so on, is a very valuable service to providers. Where services are under pressure it is essential to avoid duplication and wastage. An independent coordinator who can look across all agencies – voluntary and statutory – is in an excellent position quickly to identify overlapping services. In one case, 12 workers going into a client's home were rationalised and reduced to three active workers after a case conference.

The final, and we believe essential, part of the whole process of coordination is *checking and monitoring* to ensure that services do go in as planned. On completion of the plan we aim to follow up and check that everything is working out to the client's satisfaction. This monitoring can also ensure that any necessary adjustments are made as circumstances change and that there is an effective package of services for the client.

Once a service is established the monitoring role is further extended and a system of 'tracking' devised to ensure that people have continuing access to the service and the ability to return at any time. The whole process is therefore very fluid and flexible, with the case manager working directly with the client and constantly monitoring the progress of the plan.

The method of work described produces benefits on three levels.

1 To people with a physical disability – easy access to one defined point of help; appropriate package of services; representation; changes in circumstances catered for; long-term access to help.

2 To service providers – receive specialist planning and coordination service; ensures effective and efficient use of resources; specialist information service.

3 To the service system as a whole – receives accurate feedback of gaps in resources and needs of people with a physical disability.

Under (1), the person with a physical disability has easy access to one defined point of help and from there receives the most appropriate package of services with as much choice as possible. Also, changes in circumstances can be properly taken into account and the right to representation is catered for.

Under (2), the service providers benefit by receiving a specialist planning and coordination service with meetings arranged and plans presented based on specialist knowledge ensuring the most effective and efficient use of resources. Also, individual problems can be researched and this specialist information fed back to service providers.

Under (3), the service system as a whole benefits because the case manager is uniquely placed to feed back needs and gaps in resources to policy and decision makers.

THE PROJECT IN OPERATION (VK)

Statistics

To date we have had 150 people with physical disabilities or their carers referred to the project from an area covering two local authorities, Camden and Islington, and three health authorities, Islington, Bloomsbury and Hampstead. Anyone of any age living in Camden or Islington can be referred so long as the focus of the referral is someone with a physical disability.

We have received referrals from the following sources: statutory sector (37 per cent); voluntary sector (21 per cent); self referrals (42 per cent). Self referrals are clients who have either referred themselves directly or have been encouraged to do so by other services or other clients. The age range has been: 1–18 (1 per cent); 18–35 (6 per cent); 35–44 (31 per cent); 45–60 (33 per cent); 60 and over (29 per cent).

People have come to us with physical disabilities such as: motor neurone disease; spina bifida; cerebral palsy; muscular dystrophy; polio; multiple sclerosis; chronic asthma; heart disease; stroke; Parkinson's disease; cancer; spinal cord injury; arthritis; Stills disease; sight and hearing impairment; amputation; diabetes; Guillain-Barré syndrome; myaldic encephalomyelitis.

Case example

A 70 year old widower referred himself to the Case Manager Project on the advice of a local disability organisation. His wife had recently died of cancer and he had been discharged from hospital five months previously after suffering a stroke.

The agencies involved with the gentleman were: three social workers; two occupational therapists; two physiotherapists; the district nurse service; home help service; meals on wheels; a voluntary visitor; and a day centre placement.

The referring problem was confusion, lack of direction and so many people involved with the client that no one knew who was doing what.

The assessment carried out by the case manager – this is an ongoing process for as long as the case manager works with the client – revealed that:

> the client felt confused and felt no one was listening to what *he* wanted or what *he* needed (subsequent conversations with the many professionals involved revealed that they felt the client was capable of being more independent);
>
> the wheelchair was not suitable for the client who spent his time in one room on his bed;
>
> although the client could walk with the aid of a frame he could not get out of the room because the floorboards were rotten, the door needed widening and a ramp was needed at the front of the flat;
>
> there was family conflict because the professionals were telling them father was capable of being more independent and the client was denying this;
>
> there was a need for a community occupational therapist's assessment;

there was a need for further medical assessment.

A plan of action was drawn up with the client to:

identify DHSS benefits;

contact housing department/maintenance manager to replace the floorboards;

arrange for occupational therapy to assess for armchair and wheelchair;

liaise with hospital and community occupational therapy service;

liaise with terminal care social worker;

investigate possible treatment programme at MRC;

investigate further days at day centre;

call case conference of all professionals involved to clarify situation.

Action taken resulted in:

a case conference being called at which the situation was clarified with both client and workers with the effect that some workers withdrew (for example, the home help withdrew from carrying out basic household tasks which, once the adaptations and aids situation was resolved, the client could cope with);

suitable aids and adaptations being obtained;

a suitable wheelchair;

floorboards being mended;

a treatment programme being arranged (the client in fact decided not to go ahead with this but had the option/choice to do so);

increased days at centre as client could now get out of the flat and walk to the day centre transport provided – with a consequent marked improvement in his social life.

The case manager acted as the client's advocate in:

getting an occupational therapist allocated from the community;

applying pressure to enable the client to get out of flat;

negotiating extra days at the centre;

negotiating between the client, home help service, social services and MRC.

The case manager monitored and checked to ensure the whole plan was achieved and was responsible for coordinating the whole package of care and bringing together all the agencies so that a satisfactory outcome was secured for the client.

The benefits to the client were that he had easy access to his one defined point of help; he had choice; he had representation; and he had long-term access to help should he need it.

The benefits to the service providers were that they received specialist planning and an effective and efficient use of their resources.

EVALUATION (DP)

Case management is the connection of the client to the services he or she needs. It is intended to provide a solution to the situation arising when the services the client may need are provided by a complex variety of agencies. Case management is common in North America but only just beginning to surface in a few experimental projects in this country. The essential purpose of the Camden Case Manager Project is to overcome the problem of a bewildering pattern of services for people with physical disabilities. It is not seen as a patching up of inefficient services through funding deficiency or other causes. The project may do some of this but if this is all it does it cannot be judged a success in its own terms.

Numerous reports on the needs of people with physical disabilities point out the difficulty both for the client and for any professional trying to help a client find his or her way through the maze. Proposals for solving the problem vary as to whether it is simply a better information service that is needed, or an information service and coordinator, and in the type of coordinator. Two types of coordinator appear to be envisaged: one helping the individual client to meet his service needs; the other promoting better understanding of roles and better communication between the various professionals involved.

The case manager team argues – as the sections above show – that its method is the most effective yet devised to ensure that a person with physical disabilities receives the services most closely tailored to individual needs. It is taken from the American case manager model but adapted to the team's particular aims and client group. Central to the aims of the project is its client orientation. It is this that appears to make its independence – not necessarily a feature of case management – crucial. Independence allows the case manager's loyalties to lie entirely with the client and should make it easier to seek services for the client from any source which provides them. The connection of the client to the services he or she requires cannot take place, it is argued, without a comprehensive assessment of client needs, working out an agreement with the client on what is to be done, acting as the client's advocate if necessary to obtain particular services, and monitoring to ensure that the client is actually receiving the services. To carry out this process specialist knowledge is required of the needs of people with disabilities and of services available, both generally and specifically to those with various disabilities.

What the case manager is trying to do fits well into one of the Oxford Dictionary definitions of coordination: a 'harmonious combination of agents or functions towards the production of a particular result'. In this case the result is a package of services for the individual client designed to enhance his or her quality of life as much as possible, given the constraints of the client's physical disabilities and of service availability.

The evaluation of the project is designed to establish whether the project is carrying out coordination of services effectively. It is necessary not only to examine what has been achieved for the client, and client satisfaction, but also how it was achieved. Was it achieved because the model outlined has been put into practice or was it for some other reason such as the commitment of the case managers themselves? Where services required were not obtained was this because they were simply not available, because the case manager method of working was not able to attain them, or because the method was not actually being carried out in practice? Is the process necessary as an integral whole and if not what elements are essential? What are the advantages and disadvantages of alternative models? At this stage of the evaluation, when all the analyses have not been fully completed, it is not possible to give a definitive answer to these major questions. However, it is possible to give some indication of what is emerging.

The project's achievements for clients are being evaluated from their perspective and from that of the project team. Sixty-five per cent of case manager clients replied to a structured questionnaire which asked them why they wanted to see a case manager, what was actually achieved, why the case manager was, or was not, able to achieve what they wanted, and their satisfaction with the service itself. Over three-quarters of the clients who replied were 'satisfied' with the service; half said that the agreement on what the case manager had said that he/she would do for them had been completely fulfilled; and the vast majority that it had been at least 'partially completed'. These replies did not differ very much from those of a small contrast group of people with severe physical disabilities who had had, on the whole, good experiences with the social services. This contrast group, mainly obtained through and selected by Camden social services, consisted of people who had recently seen a social worker and/or an occupational therapist (OT) but not a case manager.

These achievements take on greater significance when it is realised that a case manager was less likely to be the first professional approached about the situation for which clients needed help than a social worker or OT – half had already approached a social worker and a third an OT. Given their satisfaction with the Case Manager Project it seems unlikely that the clients were merely searching around because they were 'hard to please' but rather that their problems were of a particularly difficult nature or beyond the scope of social workers/OTs in some way. There is some evidence – though it must be tentative because of the very small size of the contrast group – that the case managers spread their activities more evenly over a wider range of areas than social workers/OTs. An open-ended question asking what help the case manager had obtained for them mentioned many activities, such as information gathering, checking liaison, but by far the most commonly mentioned was 'putting on the pressure', suggesting that a good part of the work consisted of tasks others were having difficulty in carrying out.

Clients who thought that the case manager had been able to help them in some way were asked to select the reasons they thought most important. Their statements are set out in the table (opposite) in the order of importance as perceived by the case manager clients.

Although coordination itself is not particularly high on the list, the pattern as a whole fits in very well with the client orientation of the project and its primary function to connect clients to the services they need. In fact the top four reasons sum up well the essentials of the project, the fifth sometimes being a necessary part of the connecting process. Patterns for social workers and OTs differed from each other and numbers were too small to attribute much significance to them. Clients who thought the project had not obtained all the help they needed were asked to choose the most important reasons from a similar set of statements. Overwhelmingly, case manager clients saw the reason as the service being 'scarce or unobtainable'. Social services clients did not put much emphasis on any particular reason.

From the point of view of the individual client the project seems to have been supplying a satisfactory service. A detailed examination of the records of individual clients is being carried out to look at the roles played by the case

	%
Putting the client first always	63
Being able to approach all service provision areas	63
Knowing how to approach services/agencies	63
Being interested in the client	63
Being able to press case, represent the client	58
Personality or commitment of the case manager	53
Knowledge of specialist services for those with disabilities	51
Good position to coordinate services	49
Time to go round services	44
Has the authority to obtain services	39
Has expertise in a particular area	28

n=59

managers, differences from other workers, relationships with these workers, obstacles encountered, and actual achievements.

The third main aspect of the evaluation was to ask other service providers in the area for their views of the project. Advocacy was seen as the main role of the project, and the main reason why other service providers referred clients to it. Being an outside body was thought to be a great advantage to this role. Most service providers viewed the case manager's advocacy role with approval. But there was disquiet by some OTs – perhaps because they thought case managers might favour one client with disabilities more than another, while other service providers thought in terms of giving those with physical disabilities the same opportunities as other client groups. Coordination was seen as an important role, but it was not how other service providers characterised the project as a whole.

Various specific aspects of coordination were mentioned. Many of the service providers pointed out the role of the case manager at case conferences. It was thought that the case manager was not only able to act as the client's representative but could also help to clarify the roles of the other service providers, both to each other and to the client, when a large number were involved. As case managers are not attached to any area of service provision they were also felt to be in a good position to negotiate between the sides when there were disputes between services.

Several service providers were appreciative of the case manager's knowledge of the requirements for their services and of the difficulties under which they were working. They took referrals from them seriously because they knew the Case Manager Project would not try to palm them off with inappropriate clients.

Not all the service providers appeared to understand that a central feature of case management is that it connects the client with all the services he or she needs. Some only referred to the project for particular kinds of problems. Social workers and OTs differed in their views of how far they themselves should take this connecting process, but a number had referred to the project either because their clients' needs were for agencies about which they had little knowledge or when they felt that helping the client to look around would be too time-consuming. Several thought that case managers were less inhibited by rules and roles within the organisation in making connections. Several service providers said that case managers were more able to stay in contact with clients after making a referral than other service providers and could thus help the client to consider a number of options or make up his or her mind about a particular service.

Coordination was thus considered to be an important role for the project, but essentially it was seen as an advocacy service. Is this simply a terminological difference or does it have greater significance? A number of the service providers said that the project was in a unique position to be an advocate for people with disabilities in general – seeing so many aspects of the problems they face and being able to draw these together – and not just of the individual. The project does, in fact, have aims beyond these for the individual client. By ensuring that services are used appropriately it should enable resources to be used more efficiently. And its overview of service provision should enable it to point out where services are inappropriate, scarce or lacking in relation to the needs of people with disabilities. What does seem to be emerging is the essential relationship between provision for the individual client and these wider aspects, at least in circumstances of cutbacks and difficulties in service provision.

Further work is being carried out on the role played by case managers and their achievements from the case records. When all three aspects of the evaluation are put together it is hoped to be able to reach conclusions on the major issues. These are whether the project has actually been putting its model into practice and the adequacy of this model in meeting the objectives of providing people with disabilities with the same kind of say as others in the running of their lives.

CONCLUDING COMMENT (AA)

When the Case Manager Project was established, we wanted to obtain referrals from 150 clients. We also wanted an independent evaluation component to be built in and a report to be prepared at the end of the two years.

We have achieved what we set out to do and feel confident that the evaluation report will confirm this. We had an independent survey carried out on a small group of clients at the end of the first year asking them for their opinions on the project and a further report in the second year on GPs' perceptions of the project. Both these surveys will be included in the final report.

There is obvious interest in the role of coordinator of services for people with a physical disability. This is evident from the interest shown in our project from a variety of agencies, including health authorities, local authorities, universities, and voluntary bodies.

Such has been the response of professionals, service providers and, most importantly, the clients themselves, that we have felt encouraged to look into the possibility of becoming a full independent service. Funding is being sought from a number of sources, including the DHSS, local authorities, health authorities and major trusts.

It is our intention to create a model of coordination and advocacy – moving freely across boundaries – which is client-oriented and capable of replication nationwide. We envisage this model having a training and educative role in the case management method of work for other organisations in the field of disability.

PROJECT DISCUSSION

The reaction of service providers and voluntary bodies to the existence of the Case Manager Project was considered. For instance, were such individuals or groups resentful of the project or did they welcome it?

The project team had anticipated 'treading on toes'. Because it had no access to resources of its own, credibility with service providers was all important. This was secured during the initial period of 'walking the patch' when it became clear to service providers that the project team members were professional in their approach and existed for the benefit of clients. The team did not believe it had had anything other than full cooperation from service providers with whom it had come into contact. Indeed, the team was regarded as an ally. Referrals from professionals to the team often occurred because it was felt that an independent service was required to take a case further and to argue more forcibly on behalf of a client. Professionals also involved the team when a coordination problem arose.

More information was requested on the sorts of gaps in service provision which the team had identified. Also, it was queried how far a prescriptive medical model of care had been transformed through case management into a client-centred one. The actual alchemy needed to be described in *more detail to show the processes at work.*

The Disabled Persons Act 1986 allowed the team readier access to the system of statutory services. It became possible to call case conferences on behalf of particular clients at which the team appeared as the client's representative. At these conferences, the team members could point to problems that had arisen in the conduct of a case and could suggest changes which more closely met the client's wishes. The experience of the team had been that if professionals were approached from a base which took as its starting point the client's needs and preferences then they accepted the changes put forward. The team had the advantage of looking at a case in a holistic fashion rather than as a series of discrete components which was often the way different professionals viewed a case. An individual care plan emerged as a result of looking comprehensively at an individual's needs. Often the solution was obvious but was obscured by a fragmented service response. For example, one client had a wheelchair which was too wide and prevented free movement between rooms. Many of this client's problems centred on his restricted physical movement yet this had not been appreciated by the services engaged on the case.

Head Injuries Project, St Bartholomew's Hospital

An application to investigate the effects of a rehabilitation coordinator on outcome after severe head injury was considered by the King's Fund Grants Committee under its major grant scheme in 1986. The total cost was £240,000.

The proposal was shortlisted but the major grant was not awarded towards any application that year. The Committee, however, was convinced of the importance of the project's field of work and indicated it would be interested in a rather less ambitious, less diffuse, proposal.

A modified submission was received by the Grants Committee on 24 September 1986 and a grant of £94,000 was made to support the Case Manager for three years.

Janis Morris, Case Manager, worked as a senior speech therapist at Homerton Hospital Regional Neurological Rehabilitation Unit and as Liaison Officer, London area, for the National Head Injuries Association (Headway).

Richard Greenwood received his clinical neurological training at the National Hospitals for Nervous Diseases, St Bartholomew's and the Middlesex Hospitals, and evolved an interest in the Guillain-Barré syndrome and herpes simplex encephalitis. Awarded the Ralph Noble prize in 1978 for MD thesis 'Muscle activity during falling and stepping in man'. Appointed Consultant Neurologist in West Sussex in 1983 and Consultant Neurologist at St Bartholomew's Hospital and Director of the Homerton Hospital Regional Neurological Rehabilitation Unit in 1985. Provides clinical input to the project as a whole, and also medical advice and back-up for the Case Manager.

Lesley Murphy, Assessor, Department of Psychology, Institute of Psychiatry, London.

Tom McMillan, Advisor, Department of Psychology, Institute of Psychiatry, London.

Neil Brooks, Advisor, University Department of Psychological Medicine, Glasgow.

Graham Dunn, Advisor, Biometrics Unit, Institute of Psychiatry, London.

CHAPTER 3

Head Injuries Project, St Bartholomew's Hospital

INTRODUCTION

Severe head injury occurs most frequently between the ages of 16 and 25 when young people are just establishing their independence by leaving home, going to college, starting work, and having families of their own. Head injury can cause a multitude of difficulties ranging from obvious physical disabilities to more subtle deficits affecting personality and cognition. Suddenly the survivors of such an injury and their families are plunged into a situation fraught with problems to which there are no easy solutions, and yet a situation that can last a lifetime. People who have led normal, independent lives now find their abilities strangely fragmented, with some skills and aspects of their personality retained, some changed, and some lost altogether. This mix of difficulties is unique to severe head injury, and means that established services for the disabled cannot automatically cope with the problems posed by this group.

The head injured often recover quickly and well from the physical effects of their injury, and this rapid improvement commonly results in early discharge from hospital, with the family having been told their relative has made a 'complete recovery'. Problems with thinking skills, memory, language, and changes in personality and behaviour, may not become apparent until the person has returned to a normal home and work environment. These sequelae of severe head injury are harder to cope with than physical disabilities, and the family can feel they are living with a completely different person. Their cry is often: 'he may look alright to you, but you just try living with him'.

The day-to-day problems begin to loom large when the help has stopped, yet who can the family ask for advice who will have a thorough understanding of the difficulties they are now facing? Families begin to feel isolated, and left alone to cope with the difficulties. A series of studies by Professor Neil Brooks, Clinical Neuropsychologist in Glasgow, clearly show that the stress and burden felt by head injured families rises dramatically as time goes by, and is still rising in some cases seven years after the injury.

The head injured themselves become progressively isolated as neither they nor potential services fully appreciate the extent of ongoing difficulties. Long-term unemployment frequently occurs, and the head injured are left in a social limbo with very few friends.

Service providers often see the head injured as too complex or too difficult to treat, especially when there is a mix of physical and behavioural problems. Poor motivation or aggression following head injury can lead to non-cooperation, and services find these aspects as perplexing and frightening as do the families. Cognitive and behavioural deficits are too often cited as reasons not to treat, when they should be identified as targets for treatment in themselves. Services need considerable support and information to give them the confidence to do this.

THE STUDY

The Study began in March 1987 and will run for three years. It is designed to see whether case management is an effective way of improving the final outcome for the severely head injured and their families. It is also intended to make better use of local services already available within the hospital and community settings. The term 'services' includes the provision that is potentially available from voluntary services, local employers, recreation facilities and others. With proper instruction and support from the case manager, it is anticipated that such services can provide well for a particular head injured individual, despite having no previous experience of head injury. This uptake of local resources is of special importance since head injured survivors do not necessarily require professional health services in the long or even the short term.

At the time of speaking, I must emphasise that I have been working as a case manager in our pilot study for only five months. At such an early stage it is not possible to make any definitive statements about the effect of case management. The case manager occupies a pivotal position, providing the main point of contact for the head injured person, the family and service providers, so that everyone is in contact and the programme for the patient is properly devised and coordinated.

WHY A CASE MANAGER?

There frequently follows a series of deficits which comprise a 'hidden' handicap in that they are not easily recognised. As time after injury increases, the needs of the patient are no longer met by any single discipline but involve increasingly psycho-social and behavioural issues for which there are often no simple solutions applicable to all patients. Once discharged from the hospital, the head injured person needs his own personalised programme, implemented locally, and needs to be steered through the range of services potentially available. If return to work can be contemplated, success depends firstly on early and effective contact with the employer, and secondly on devising a programme which details exactly how much the head injured person can cope with and what his duties should be.

To be effective in their provision for the head injured, existing facilities need regular information, guidance and support. Good communication between all the services involved is essential so that knowledge and difficulties can be pooled and shared. It is proposed that a case manager experienced in the field of head injury could educate and counsel professionals and families, and match and maintain facilities with patients so that individual needs are met. My discussions with various services took place prior to 'hands on' case management, and comment was made to the effect that case management was really the role of the social worker or the GP. This is very definitely not so, and in fact when I stopped talking and began working as a case manager these same services were the first to agree that the role was entirely separate.

Currently it is often luck rather than judgment that dictates whether people get the services they need. Many severe head injuries are first treated in a neurosurgical unit (NSU), where in addition to the essential medical, surgical and nursing care, they will routinely receive physiotherapy. Other services are likely to be of benefit at this stage, but as there is no one to identify exactly which ones are appropriate, the referrals are rarely made. Once transferred to a district general hospital (DGH), paramedical referrals are again not routine, and the patient may be 'housed' on a ward where medical and nursing staff have little or no experience of head injury. A case manager takes responsibility for making appropriate referrals.

If the patient is transferred to one of the handful of rehabilitation units in this country, what will happen after discharge? The rehabilitation team may set up a home-based programme, but who will implement it, make sure it is working, and keep things running smoothly? Once the person goes home, whose responsibility do they become day to day, and what services will be enlisted? If there is a real possibility of a return to work, who will set this up in such a way that the person is most likely to succeed? All these matters are the concern of the case manager.

Many head injured people with severe long-term disabilities end up on a variety of wards such as orthopaedic, geriatric and psychiatric. This sad state of affairs occurs either because the person has not received proper rehabilitation, or because the residual effects of the head injury are difficult to cope with in the home setting. This most commonly applies to behavioural disorders. Long-term placement in a hospital ward wastes acute health sector resources, and is wholly inappropriate for the patient.

In the course of my work with Headway, the National Head Injuries Association, it is clear that families come into contact with many different people in the months and years following injury. They complain bitterly about the fragmentation of services and that there is no one who has seen them through from the start. The case manager is able to change this.

GUIDELINES FOR CASE MANAGEMENT

Social workers, GPs and therapists can at best assume the role of 'coordinator' or 'key worker' in terms of maintaining good liaison, but it is impractical for them to continue such a role in the long term.

Social workers, especially those working in the community, may have little or no experience of the problems faced by the head injured, and it is certainly not their role to make recommendations regarding rehabilitation. No single GP will see enough head injured patients to build up an expertise, and the time alone involved in case management precludes GP involvement at this level. A therapist's main responsibility is for restoring or improving specific skills at a particular stage in the recovery process. Each therapist forms an integral part of the treatment team.

A case manager not only liaises, but also assesses, directs and counsels. This person will from time to time set up a treatment team to include a social worker, GP, several therapists and others, but will not be an integral part of that team. During the course of rehabilitation a head injured person may see many therapists, several social workers and perhaps one or two key workers or coordinators, but there should be a single case manager. The case manager will work with each team in goal setting and will be there when change is needed or when things go wrong.

The case manager acts on behalf of the patient. In the early stages, patients and families are unaware of how great their needs are likely to be in the future, so case management is provided as a matter of course along with the acute services, and is not presented as an optional service. The importance of this approach is highlighted in the case history I will be speaking about later.

The case manager is responsible for the best quality of life outcome. While there is evidence to suggest that recovery may continue for several years, in practical terms it is envisaged that case management in most cases would be of particular value in the first two years post-injury. During this time the case manager will plan and implement a rehabilitation programme to cater for individual needs, and service delivery will happen by design rather than by default. Despite this, case management is not a cure-all. A satisfactory outcome can range from a residential placement for the very severely disabled to a successful return to work for others. What is important is that each person is offered a tailor-made rehabilitation programme and that the family is properly informed and supported throughout so that, given the severity of the initial injury, both patient and family are able to come to terms with the final outcome.

CROSSING BOUNDARIES

To work in the best interests of the patient it is essential to have the freedom to work across all possible boundaries. The case manager can decide upon and coordinate a programme for each person; he can take things much further than the services at grass root level. To do this is very important, and demands considerable knowledge of head injury on the part of the case manager.

Employees working in health or social services sometimes feel, rightly or wrongly, that there are limits beyond which they must not go. Sometimes these limits are real but occasionally the case manager as an 'outsider' can make a suggestion not normally considered in the usual run of things which can be satisfactorily acted upon by a member of the treatment team. In theory, the concept of case management could be perceived as a direct criticism of current services instead of a tool to enhance their effectiveness. In practice, case management has so far not been seen as a threat but rather as a facilitator for obtaining the most effective help.

The long road towards a recovery can resemble a maze. Everyone in the system does their best to set the patient along the right path, but sometimes it is difficult to know which turning to take. The therapists ask 'shall we go this way or that way?'. As a doctor, a nurse or therapist in the maze you can only see a little way ahead, and cannot really know what is around the corner because you are unable to go with the patient. On the other hand, a case manager can go around all the corners with the patient, and can get up in a helicopter and look down on the maze from above to see where the patient is now and where he should be eventually. Armed with this information the case manager can plan the most direct route through the maze and prevent the patient from getting lost.

Many patients do not experience any problems until they go home, so I frequently have to start alone from scratch in building up a rehabilitation team. Once I have drawn potential team members together, life becomes somewhat easier as ideas are discussed and resources pooled. Yet this may be just the first of several 'teams' that each person will need. Pinpointing requirements and making choices are specific to the role of the case manager, and such tasks do not imply gaps in the present system.

CASE HISTORY

A single case history cannot hope to illustrate the vast range of difficulties created by severe head injury. Each head injured person will suffer a unique pattern of deficits, yet there are some factors common to many.

John is fairly typical of the large number of young head injured people who make an early and complete physical recovery but suffer a variety of 'hidden' handicaps. At age 24 and a week before his wedding, John suffered a severe head injury. He was taken to the local DGH and immediately transferred to the nearest NSU. He was unconscious for about five days and he had an estimated post traumatic amnesia (PTA) of about 14 days. I first saw John and met his family when he was in intensive care at the NSU. At first the family were rather suspicious of me, and I realised then that the apparent desire expressed by many head injured families to have someone able to follow them through from the beginning was probably a retrospective wish, since these families knew what it was like to cope alone for many years with the lasting effects of head injury. If case management had been presented as an optional service at this stage, then John's family would surely have turned it down.

John had been conscious for two days when I was informed by the sister on the ward that he was to return to the local DGH. The family were naturally anxious about this transfer, particularly as they would have to get used to a whole new set of staff. It was at this point they realised that I would be the single link between the two hospitals, and that I would continue to see John in the DGH. The medical and nursing services at the DGH welcomed the detailed information I provided for them from the NSU, and I was able to speed the exchange of information between the two sets of therapists.

On transfer John was physically recovered but much of what he said did not make sense, and he was very slow to do simple things like washing and eating. In the absence of any major deficits, he was not a priority for the hospital-based therapists, so I referred him to a rehabilitation unit. He was not accepted because it was thought that by the time a place became available he would be 'too good' to benefit.

By this time the family thought that John was 'fine' and 'perfectly normal'. I suggested to the medical staff that John should go home for the weekend, and I spent time talking to the family about some of the difficulties John might experience during this time. They still maintained that he had made a complete recovery, but when he returned to the hospital on Monday morning, they were only too aware of the changes in him. They wanted to know what was going to happen next because John was still quite obviously far from recovered.

John no longer needed the services of the DGH, so I suggested discharge to his consultant. The consultant was pleased that his orthopaedic bed would be freed so early, as someone like John generally stayed several weeks longer on the ward simply because no one quite knew what to do next. On discharge he was walking, talking and managing basic daily skills, but performed none of these with the zest and flair that were part of his personality pre-injury.

John's girlfriend, Sue, was his main carer although his parents had daily contact. John had problems with insight, and in initiating and performing activities properly. He misinterpreted people's feelings and reactions, and made inappropriate comments at the wrong times. He could not plan things properly or select out the important aspect of a situation. These difficulties had far reaching effects at home, and meant that John was unemployable in his previous work. Sue found that unless she continually prompted him to do things he would just sit and do nothing very much.

In addition to the wedding plans having to be temporarily postponed, Sue had to cope with the trauma of the injury and its effects. Inevitably, she became tearful on occasions, yet John had no appreciation of why she should be upset. He was unable to comfort her.

Prior to the injury John had been loving and attentive and had made all the decisions, so the many subtle changes that Sue now noticed, while insignificant on their own, amounted to a major change in the man she planned to marry. Furthermore, she realised as time passed that many of the attributes which she loved about John were in her eyes no longer there.

When John first returned home, I had frequent contact with Sue and his family to establish how his needs and their own might best be met. After about two weeks at home a speech therapist and an occupational therapist seemed the best people to target. The two therapists I contacted were very willing to help John but the occupational therapist had no previous experience of head injury. They asked for specific information and guidance from me. We met regularly to identify goals for treatment and to monitor John's progress. After several weeks both therapists agreed John would benefit from further help.

I found another rehabilitation unit prepared to take John. While he waited for a placement I suggested to the occupational therapist that John might work as a volunteer in the hospital League of Friends shop. A meeting was set up to include the volunteer organiser as well as the therapists, and a programme was jointly devised which the occupational therapist agreed to supervise. This is a good example of the way in which services can be joined together and enabled to provide an innovative scheme for a particular individual. Everyone wanted to further John's recovery, and as this was the focus of attention each person adapted and shared their own skills to meet John's needs. John did not meet the criteria for the average speech therapy or occupational therapy patient, and he was certainly not an average volunteer for the hospital shop, yet the two therapists offered him help with specific skills while the volunteer organiser offered him some real life work experience in a structured and sheltered situation.

John has now spent a month in a residential rehabilitation unit where again I have regular contact with the staff. The purpose of this placement is to help him improve social and work skills. It is likely that John will be employable in the future, but it is too early to predict in what capacity. I have already seen his present employers to keep them informed of John's progress, and to maintain their interest in his recovery. A previous employer with whom he worked in a less pressurised capacity is willing to take him back temporarily to provide some preliminary work experience.

On discharge from the rehabilitation unit I will devise a graded work schedule with the earlier employer, and later with John's current employer. His duties, responsibilities and hours will be carefully controlled in order to give him the best chance of a successful return to work in the long term. It is important that John and his employers initially view his return to work as the next stage in the rehabilitation process, rather than as a direct return to full working capacity. This concept is helpful in providing both employer and employee with realistic expectations. Gradually I would expect John to cope with increasing demands.

Of course John is still far from reaching a 'final outcome', yet without case management he may already be floundering. It is likely he would have been discharged from the DGH without rehabilitation, and without information and support for his family. This would have occurred not through neglect on the part of other services, but because there is no one else in the system of service delivery who can assume this role. John could easily have remained unemployable.

CONCLUDING COMMENT

The study is still in its infancy, but already the indications are that case management provides a necessary and unique service, in no way duplicating the roles of others. For the head injured and their families, the value of a case manager becomes increasingly apparent as time goes on. The role assumes increasing importance when the head injured need to re-establish themselves within the family circle, and vocationally. Case management is concerned with putting together innovative individual packages.

Service providers have not been slow to utilise case management. For instance, a doctor had decided to discharge a head injured patient; I said this was probably unwise and gave my reasons. The next day the medical file stated that she should not be discharged until permission had been given by the case manager. On another occasion I was contacted by a doctor in casualty in respect of one of my patients who had turned up complaining of various post-traumatic head injury symptoms. On reading the medical file, the doctor had found the patient was being case managed and had recently been an inpatient in the same hospital. It was logical and appropriate that he should contact me for an update on the intervening period, and to discuss the advisability of readmittance.

GPs, solicitors, employers and others have contacted me, with comment to the effect that a case manager is such an obvious person to provide help and advice. To quote a community physician, case management is 'such a sensible idea'. Therapists and nurses too have expressed a willingness to learn more about head injury, which is good news for the future success of case management.

PROJECT DISCUSSION

How were referrals made to the case manager?

The independence of the case manager was very important, but since the services were concerned about who the case manager belonged to, it was best in the first instance for the case manager to be allied to the consultant, since he was still recognised as the head of the team. A blanket referral system operated with all consultants who had severely head injured patients in their care. Services that questioned the case manager's involvement were satisfied by the consultant link. As time went by and patients moved away from the hospital setting, this link assumed less importance and it was then possible to contact a service as a patient's case manager and be fully accepted without strings attached.

Concern was expressed at the case manager having to break the news that there was going to be long-term consequences for the family featured in the case history. Was this not the doctor's responsibility?

The doctors could not undertake to do this, although in practice some of them did. They had to remain open in their prognosis because in the very early stages it was difficult to know exactly what would happen. Doctors varied in the amount of time they spent talking to families, but there was a limit to the amount of information a family could absorb at a particular time, and doctors themselves had limited time to spend on this task. Because acute services were under pressure, families were talked to by lots of different people and this meant they often received crossed messages. Hospital staff were keen that the case manager should become the main point of contact for the family. Families required time to absorb the information they needed. A case manager was able to support them on a day-to-day basis and could play the situation by ear. Dissemination of information depended a great deal on the personalities of the family and staff members involved in individual cases.

The issue was raised of possible conflicts between the wishes of the head injured person and those of the family. These need not necessarily coincide.

A case manager must use judgment in balancing the wishes of the head injured person and the family when they differed. Ultimately the case manager's responsibility rested with the patient. At first the head injured and their families neither knew what they needed nor what was available. A case manager should identify and present the available options but must then steer them gently towards the best options. Lack of insight often led to differences in the aspirations of the head injured and the family. The case manager should attempt to unify these expectations by exercising skill and judgment.

The development of the case manager role was discussed in the context of the case history. It was suggested that John's girlfriend might be beginning to feel that a long-term relationship was in no sense a practical proposition and that she ought to end it. However, this could induce feelings of guilt. How would a case manager respond in such a situation?

In these early months, following John's head injury, Sue required considerable emotional support. John's deficits were relatively subtle and this meant that her family and friends were unable to appreciate the pressure she felt. Sue found it difficult to express her feelings, and was therefore reluctant to speak to anyone other than the case manager whom she had known from the day after the accident. Sue did indeed have doubts about the future of her relationship with John, and there were almost daily changes in her ideas about how to resolve the situation, ranging from a desire to marry him immediately to feeling she should leave immediately. The hardest thing was living with the uncertainty about the extent of his eventual recovery. The case manager was there as a sounding board and in order to maintain the status quo until Sue could make a proper decision.

This time was difficult for all families of the head injured and there were no quick or easy solutions. It was important not to try to find easy solutions, but rather to provide practical and emotional support until the family began to cope with their own feelings a little better. Services too found it hard to cope with uncertainty or in admitting to themselves and to their patients that they did not know all the answers.

Unlike the Camden Case Manager Project, the severe head injuries initiative revolved around one person dealing with a specific type of injury. It was suggested that there might be merit in becoming part of a Camden type service with a focus on a wider category of patients. The Camden group had one or two head injury cases but also many different types of patients.

Two rather different types of case management were at work in the two examples. The head injured group had particular needs which were difficult to cater for, but services were more likely to cope provided they had sufficient information and contact with the case manager. There was a need for a specific response to particular conditions, in preference to a generic approach which ran the risk of becoming diluted. In other words, case management should be selective. This was particularly true of the head injured group.

The issue raised wider concerns about the precise nature of case management. The Camden team suggested that case management should be seen as a method of work. There would be individuals within the orbit of case management who would have a special interest in, say, physical disability. Generic case management was not appropriate but specialisation was possible within the concept of a shared method of work. The fact that there was a dialogue between the two initiatives suggested an acceptance of this point of view. There were, after all, many groups of people, such as those with cancer or mental illness, being supported by multiple agencies where similar problems could arise to which case management was seen as a solution.

The issue of caseload was raised. What size of caseload was optimal for the case manager without her being overloaded?

There did not seem to be any point at which the case manager could quickly exit from a case. Many cases were likely to continue for a long time.

It was not the intention that the head injured and their families should be dependent on a case manager indefinitely. Different patients and families varied in the demands they made on the case manager, but in general terms the most intensive input was required on discharge from acute services. Various peaks and troughs occurred in the need for case management but the peaks gradually lessened.

Over the days and weeks families alternated between occupying a background or foreground position in the case manager's case load. It was difficult to be specific about the number of cases it was feasible to handle at any one time since pressures shifted daily.

Evaluation of the project was seen to be important.

The intention of the study was to compare a set of case managed districts with a set of districts not case managed. A psychologist acting as assessor would follow patients from all the selected districts and, using various outcome measures, try to ascertain after a period of time whether the case manager's impact was measurable. The hope was that an effect would be shown in favour of case management.

Disability Team for Westminster and Kensington and Chelsea

An application from Victoria and Paddington and North Kensington Health Authorities with a proposal to establish an adult handicap team on an action research basis to service the two health authorities was first considered by the King's Fund Grants Committee on 11 April 1984. The total cost of the proposal was £60,000 per annum for four years.

The Committee expressed an interest in the proposal but agreed it required some modification and a reduction in costs.

A more modest, revised proposal was received by the Grants Committee on 25 April 1985. The request was for the appointment of a coordinator for the Adult Handicap Team, to serve Victoria (now Riverside) and Paddington and North Kensington Health Authorities, at a cost of £11,500 per annum for three years. A grant of £34,500 was made.

Felicity Nichols, Team Leader, worked as a speech therapist at St Mary's Hospital, Harrow Road, London, specifically with people with neurological disabilities, before joining the Disability Team in February 1986.

CHAPTER 4

Disability Team for Westminster and Kensington and Chelsea

INTRODUCTION

The Disability Team is a community-based, multidisciplinary group concerned with physically handicapped people between the ages of 16 and 65 living in the boroughs of Westminster and Kensington and Chelsea. The health authority has rented office space for the Team in the Disabled Living Foundation.

The project was set up for three years in the first instance and is funded until February 1989. Funding for the Team has come from the health districts of Paddington and North Kensington and from Riverside (East), and the King's Fund provided a grant for the Team Coordinator's post.

Disability is defined by the Team as 'the limitation of functional ability which results from an impairment due to disease, disorder or injury'.

The Oxford Guide to the English Language defines the verb 'to coordinate' as 'to bring into a proper relation; cause to function together efficiently'. The term 'coordinator', therefore, can be applied in a variety of different contexts and I will mainly discuss two aspects of coordination in relation to the Disability Team: one is the coordination of services as part of the Team's overall brief; the other is the coordination of the Team's work and the role played by the Team Leader.

SETTING UP THE DISABILITY TEAM

The idea for the team is based on Ahilya Noone's research (1981). Her paper was about the needs of the younger disabled people in Westminster and Kensington and Chelsea with particular reference to the provision of residential care.

It was written shortly after the new younger disabled units were built during the 1970s and a younger disabled unit was one of the options being considered in the area. At that time the only provision for people who needed residential care in the two boroughs was the use of contractual beds in the Royal Home and Hospital for Incurables at Putney (RHHI).

On the basis of her research Dr Noone identified the following problems:

> The absence of any local provision by the NHS or local authorities of residential care and a degree of unmet need.
>
> That there will always be groups of severely disabled persons for whom special decisions about placement will have to be made – for example, unconscious persons, those with behavioural disorders, psychiatric illness.
>
> Few professionals are in contact with the severely disabled in the community and little is known about them until crises force the issue.
>
> There is no central source of information about services for the disabled and their availability.
>
> There is a strong feeling among caring professionals that a service which reflects the expressed wishes of the client is desirable.
>
> A recognition of rapidly changing attitudes about disablement throughout the community at the present time. (Noone 1981)

Dr Noone stressed that any recommendations should address these problems and that, at the same time, the approach should be flexible and innovative in view of the last two problems noted above. She felt an answer might be to have a multidisciplinary team with both a service provision and assessment function.

Her recommendations were as follows:

A *Service*

The provision of assessment and advice to disabled persons either at the centre or on a domiciliary basis;

planning individual care programmes.

B *Planning* In addition the staff and management team will:

collect information about severely disabled local residents and their needs;

plan future service developments;

monitor and evaluate the resource centre;

keep abreast of national and local developments in the care of the severely disabled;

liaise with other local authority and voluntary organisations which contribute to improving the lifestyle of the disabled persons especially in the field of employment and housing.

The lack of coordination within the services was further borne out by the research published by Thomas and others (1987). In fact, the data for the research were collected in 1984–85 (just before the Disability Team was established) and they compared the provision of support services for handicapped young adults in a London health district with those in a rural district.

The sample from London was taken from Paddington and North Kensington and the following points were made as part of their recommendations:

> The reduced contact with the health service and lack of support from the local authorities is likely to be for three main reasons:
>
> poorly organised services and lack of trained personnel;
>
> lack of communication and coordination between the health and welfare services resulting in imprecise details of the number and needs of handicapped people in the community;

> a paucity of information easily available to the handicapped individual which can, in turn, lead to a poor takeup of the available services.

The researchers stressed that the samples were representative of most health districts and were not only a criticism of the two health districts studied. They went on to recommend the implementation of adult handicap teams similar to the child development teams which coordinate the paediatric services.

They also made the following points about such a team:

> General practitioners should continue to provide primary care. However, given the complexity of many handicapping conditions specialist advice and backup services are a necessity. This multidisciplinary team should include a physician with experience in the management of handicap and apart from routine medical assessment this team should be able to offer advice and services for particular medical problems such as urinary incontinence, bowel management and pressure sores as well as providing or arranging referral for occupational therapy, physiotherapy, speech therapy and sexual genetic counselling. Advice and assistance with social problems relating to housing, employment, mobility, finance, leisure, further education, training, and day placement should also be available through the proposed handicapped adult team.

In 1985, Dr Noone's research was used to put the idea of a multidisciplinary team before a steering group which consisted of officers from two of the health authorities involved and the two local authorities. It was decided that the Team should be in existence for three years and should consist of a core of therapists, a nurse and an administrator. A clinical psychologist and social worker were to join at a later date. As a result, The Team leader was appointed in October 1985 and the administrator in February 1986. The physiotherapist, occupational therapist and nurse were appointed by the following August. The clinical psychologist came into post in September of 1987 but, unfortunately, no funding became available for a social worker. Originally it was also hoped that the Team would have a specialist consultant in physical handicap in younger people, but again this has not been possible because of lack of funding.

AIMS AND OBJECTIVES OF THE TEAM

The aims and objectives were set by the steering group in May 1986.

> To identify, examine and assess the needs of severely handicapped individuals aged between 16 and 55 with home addresses in Westminster and Kensington and Chelsea and who may be being considered for residential care.
>
> To examine and assess, in conjunction with relevant people, the needs of the younger physically handicapped in residential care in order to decide whether that individual may be appropriately placed in the community.
>
> To provide a peripatetic service offering assessment, advice and treatment where appropriate; to coordinate the existing available services to make the most effective use of them.
>
> To be a resource centre.
>
> To consider the production of a register.
>
> To plan the future service for the group specified in the first aim and advise the district general managers and directors of social services accordingly.

Treatment was included in the Team's original brief. However, it became evident that it was not possible for the Team to carry out treatment as well as fulfilling its other functions.

The coordination of services, as outlined in the third aim, follows the Team assessment of the person's needs. This can sometimes be difficult for other professionals to accept and at first people were mistrustful about the Team's existence since it seemed to imply that something was wrong. But the

Team tried to put across the point that it was there to support other services and not to take over or to criticise them. In order to do this we had quite an extensive public relations programme which involved sending introductory letters to hospital departments, community staff and social services. We also did a great deal of follow up talks. A leaflet was published which was principally aimed at disabled people themselves in order to encourage self-referrals and these were placed in, for example, clinics, GPs' waiting rooms, Citizens' Advice Bureaux and libraries.

The resource centre mentioned in the fourth aim is also an important aspect of coordination. The Disabled Living Foundation, in which the Team is based, is obviously an excellent source of national information and we often use their data for reference. However, the information we have collected is geared towards local services and can easily be accessed and passed on to our clients or other professionals.

It is vital to the overall coordination of policy for disabled people that information gained from the Team's work is relayed to the service planners. This is another aspect of coordination which is outlined in the final aim of the Team's brief.

COORDINATION IN PRACTICE

A The coordinating role of the Team

A useful aspect of coordinating the services as a Team is that each discipline can liaise with the relevant person involved and that is quite helpful in gaining as clear a picture as possible of the client's abilities and difficulties

Transition from hospital to the community There have been cases where plans for clients have been made while they are in hospital – such as outpatient therapy, the ordering of equipment, or frequency of domiciliary services. But these services do not always happen, perhaps because transport does not arrive or for other reasons. It has therefore been useful for one or two members of the Team to attend the case conference at which the management plan is discussed before a person leaves hospital and they can then help to ensure that the plan is carried out when he or she returns to the community.

Transition from hospital to a continuing care bed In many cases the only possibility considered for people in Westminster and Kensington and Chelsea who need residential care is a bed in the RHHI. It is obviously important that if a person has to spend the rest of his or her life being cared for then the choice of continuing care must be as positive as the resources allow.

The Team can do the 'legwork' in investigating the possibilities and relies on the social worker to maintain contact with the client and the family within the hospital setting. In this way, hopefully, the most appropriate choice of place is made while time is allowed for counselling the client and family for the enormous life change which has to be made.

Coordination within the community The Team is able to monitor and evaluate the plan of care which has been set and it remains a point of contact for people with disabilities and others involved in their care. All the cases are kept under review so that if the situation changes, the management plan can be altered accordingly. The contact is maintained either by review appointments or the client can telephone the office if the need arises before the review date.

Transition of the young adult from the paediatric services to the adult services The transition from paediatric and school services to the adult services is often an extremely difficult one for a disabled young person and his or her family. It is most usually a time of enormous tension anyway because of the pressures which are brought about by adolescence, and it can be quite frightening for the family to find itself cut adrift from the child development teams and paediatricians who have worked with them in the past. Often there is no consultant involved and the GP may not have specific knowledge about the aetiology of the disability. It is therefore helpful for young adults to be referred on to the Disability Team where they and their parents can continue to go for reference and advice.

B The role of the Team Coordinator

As Team Leader I am responsible for coordinating the day-to-day work. In order for a team to work together effectively it is important that some time is given to making sure not only that the work is carried out but that everyone within the team feels happy about their individual role and also their contribution to the overall goals of the team. The role of Team Leader involves the following tasks:

Chairing Team meetings It is important to make sure that everyone in the Team has a say during Team meetings and also that support is provided from the rest of the Team for those working with difficult cases.

Ensuring referrals are acted upon Referrals are either telephoned or written and are then allocated at the weekly Team meeting. Each referral has a key worker and she and another Team member carry out an initial visit. Before the initial visit it is the job of the key worker to telephone any other people involved with the care to obtain relevant information.

A care plan is then formulated based on the initial interview with the client and carer and this is also drawn up at a Team meeting where the benefit of everyone's knowledge can be utilised and then other services notified if necessary.

Ensuring Team members are clear about the aims and objectives and that this policy is being acted upon Any group of people working together are bound to have different ideas about how the group should be working. It is helpful if all these ideas are aired during discussions about sticking to the aims and objectives.

Liaising with other teams, voluntary organisations, and so on This is an important aspect if the Team is to work effectively within the existing services.

Liaising with higher management The Team Leader is invited to attend steering group meetings and to have regular meetings with the Manager for Disability Services, Paddington and North Kensington Health Authority.

CONCLUSIONS

The term 'coordination' can be applied to almost all levels of disability, from the aspects of service provision within the community, through the coordination of groups of workers themselves, to the umbrella aspects of management and planning. Not only does there need to be coordination and communication between different services but also from the top down and vice versa within each echelon of service provision. Ideally, of course, it is the client who should be the principal coordinator in the immediate service provision and in helping to plan services.

The Team's role as coordinator within the community has developed a great deal over the last two years. At first a lot of time was spent on public relations and, as a result of this, the coordinating aspect of the Team's work has developed during the second year as other service providers have come to know and trust us. As a group of people working together and by utilising different professionals' ideas and assessments we hope to provide a holistic approach to a person's care. As coordinator of the project I try to ensure that these aspects work well together and that our ideas for the most appropriate development of the services will be taken into account by the planners.

PROJECT DISCUSSION

It was suggested that the Disability Team dealt with general disability issues as well as with individual clients.

This was accepted as being the case. All clients referred to the Team were seen for as long as they needed to be and were kept under review.

Mention was made of the Team perhaps having more of a case management focus than was apparent from the discription of its work.

It was argued that the problems of coordination had to be seen on a health district or local authority wide basis. There was a need for both approaches since they were complementary. However, the Team played rather less of a 'hands on' case management role (unlike the other two initiatives considered) and acted much more like a pressure group persuading other professions to work in a way that would better meet clients' needs. The Team's remit was a complex one. It had the potential advantage over the other two schemes of influencing planning at an agency level, although in practice such influence remained rather weak and undeveloped.

Concern was expressed at a possible conflict of interest arising from the attempt to operate at different levels – that is, at the level of management and at the level of the individual. Conceivably, there could be a conflict of interest between the liaison work with senior managers on the one hand and the attempt to represent and put clients' wishes at the forefront.

Possible tensions in this area had not surfaced so far. Working *within* the health service could make it awkward for the Team to criticise those services, but it had not yet proved to be too much of a problem. Team members worked on a personal level with other service providers. The management side of the Team's remit was perhaps more difficult. The Team is an unusual concept without precedent. The managers did not know where to locate the Team.

Before the Griffiths management changes the Team existed as a separate entity. Following the changes, the Team had to be fitted somewhere into the structure.

The issue of the accountability of Team members was raised.

Team members were managerially accountable to the Team Leader but professionally accountable to their district heads. In terms of the Team's overall brief, the Team Leader was its manager but if a professional problem occurred then a Team member could refer this to the appropriate district manager. The Team Leader was accountable to the manager of disability services and to the steering group.

Information was sought on how neurologists used the Team and vice versa.

Neurologists did not refer directly to the Team. At St Mary's Hospital many of the neurology patients came from outside the boroughs covered by the Team. All appropriate referrals were passed on although there was not a formal procedure. If a patient had an appointment at neurology, and if it was appropriate to be in attendance, then a Team member accompanied the patient. This could sometimes be helpful.

A description of the work of the Team and any deficiencies encountered was requested, particularly given the absence of a social work member, the attempt to influence managers, and the limited amount of direct casework carried out.

Many of the problems arose from the Team's origins. It was set up by the health authority but without any formal agreement with social services. Yet because much of the Team's work was carried out in the community, many of the services were provided by the local authority. A basic problem, then, was whether the Team was a health team and from where it actually originated. If the Team had had a social worker it would have been much easier to liaise with social services departments. It was accepted that social workers needed to be involved in some capacity with many clients.

There was a request for a brief history of a typical case that might be referred to the Team in order to illustrate its approach.

An example was given of a case concerning a patient in hospital with multiple sclerosis. The patient regularly had to return to hospital. He was very ill and was referred to the Team because he was unable to cope at home. He had been visited by a community physiotherapist but this was some time ago and his case had not been reviewed. He was having difficulty with his speech and the GP referred him because he did not know what to do with him. The Team assessed him and found he had degenerated a great deal and could benefit from more physiotherapy and speech therapy. The Team became involved in the case because the patient had deteriorated quite rapidly. Each hospital admission resulted in all the services stopping, so case conferences in the hospital were attended by the Team where plans were laid for the patient's return to the community. The Team saw its task as ensuring that these plans were implemented. It did this by visiting the patient at home and by ensuring that the appropriate support was being provided as had been agreed. Initially, Team members were involved in the provision of treatment as well as carrying out assessments in order to make recommendations to other therapists.

PART III
DISCUSSION AND ASSESSMENT

CHAPTER 5

General Discussion

Discussion was structured around a number of issues and questions derived from the background paper (see chapter 1).

1 *The issue of terminology is problematic. Can a more precise definition be offered of terms like 'coordinator', 'key worker' and 'case manager'?*

The terminology of 'case manager', 'key worker' and 'coordinator' is a cause of considerable confusion. A key worker, as opposed to a case manager, is someone who serves as the main point of contact for the patient and their family and the rest of the team for a specific period. There may be several key workers if a patient transfers between services. In contrast, there is only one case manager. The main difference between a key worker and a case manager lies in the fact that the case manager takes an overview of the case and is not a member of the therapeutic team involved in a person's treatment. The role of case manager goes beyond the immediate confines of a case or service setting. In addition, the client figures more prominently in a case manager's brief since he or she is the person to whom the case manager is primarily accountable. In contrast, a key worker is accountable to another professional and, although unlikely, can ignore the client's wishes. A key worker exists to facilitate the delivery of services to a patient and, in this sense, may be there more for the benefit of providers than of clients.

There is also a distinction to be made between a case manager and a coordinator. Whereas a coordinator liaises with people, the case manager has a more directive role in regard to a client's needs. Case managers do not merely liaise but are responsible for pushing things forward and getting things done. Coordination is a component of case management (as, indeed, it is of the key worker role) but they are not one and the same activity.

There was general agreement that whereas any professional can operate as a key worker or a coordinator, case managers tend to be freestanding and act as 'conductors of the orchestra'. However, there are examples (the three schemes supported by the King's Fund are not among them) where case managers belong to existing services. One example, and perhaps the best known, is the Kent Community Care Project and its variants elsewhere in England and Wales.

It was suggested that a major difference between the Kent model and the examples being considered at the conference is the absence in the former of client advocacy or representation. It is difficult for a case manager to act as an advocate for clients if, at the same time, he or she is part of the service system with which a client is in contact. A conflict of interest can arise. It is also the case that the Kent project had limited involvement with health services. However, other examples of case management, such as the Darlington Home Care project, do explicitly link health and social services together around the needs of clients.

2 *Case management might operate* either *at the level of practice as a means of securing a holistic view of client/patient needs, of matching these to available resources (which may or may not be controlled by the case manager) and of representing these in an advocacy mode* or *at higher levels as a planning and management strategy to cope with resource pressures – that is, perhaps to do more with less. Difficult issues and problems arise at each of these levels.*

If the root problem is service shortage rather than gaps or duplication what impact can street level case managers successfully make?

Is there a symbolic dimension to such activity in these *circumstances with only the faint prospect of practical gain?*

Is there a need for case management at different levels or would this be a recipe for conflict?

Of the three schemes considered, the disability team at Westminster and Kensington and Chelsea operates at a higher strategic policy level than either of the other two which are located at practice or case level. Because of the different levels of functioning, case management involves rather different approaches at each level. A problem may arise in trying to combine both a strategic and a practical role in the same initiative.

3 *Under the rubric of coordination, or case management, a variety of outcomes is claimed to flow from it: increased efficiency, accessibility, accountability, advocacy, comprehensiveness, participation, to name a few. All of these are worthy goals but they are not the same and different objectives might imply contradictory courses of action in a given instance.*

If it is accepted that these goals are all desirable but potentially conflicting where could/should coordination/case management make an impact?

It was agreed that there are difficulties in balancing the various outcomes but that it is important they be resolved. Although the primary aim of case management is to support the client, the case manager has to have regard to the prevailing statutory and financial realities. Nevertheless, trying to satisfy the client's best interests while at the same time expressing concern for the interests of service providers and being mindful of the resource implications could prove virtually impossible. At the end of the day it may be necessary to choose whose interests should be uppermost. In this situation, it is essential that the client's voice be heard in the hope that this will lead to policies and decisions which are more closely tailored to what the client wants.

It is likely that case management could reveal more instances of service gaps than of over-provision. An example was cited where 11 providers allocated to a client had been reduced to three as a result of case management. More often, the problem is a gap in provision.

The additional cost argument resulting from successful case management should not be overstated. Quite often what is required is a modest reorientation or adjustment in the way a service operates which does not involve additional cost. A case manager can assist services to modify entrenched ways of working and overcome professional myopia which do not meet client needs and which are therefore wasteful of resources. The case manager is in an ideal position to investigate substitute forms of support. The Kent scheme (see above), for example, functions in this way. Quite often a blockage in one service is resolved by looking elsewhere and possibly coming up with a different solution to the problem. A coordinated approach, whereby all services and resources are reviewed in relation to each individual client, is more likely to lead to an appropriate use of available resources than services and providers working in isolation from each other and possibly duplicating efforts.

4 *Common solutions to common problems probably do not exist. The three coordinator/case manager schemes are products of their respective environments – they are 'bottom up' rather than 'top down' responses to perceived problems in each locality. What might work in one locale might be less successful or even fail if transferred and imposed elsewhere without adaptation to fit local circumstances.*

While it is possible, indeed essential, to learn from successful initiatives how can this best be done?

It is quite true that common solutions to common problems do not exist. Nevertheless, despite the fact that the three initiatives each display differences in their design and operation it was felt that case management as a general device has much to commend it in other client group settings. The example of mentally handicapped people was given where patients are being returned to the community as hospitals are being rundown and closed. Often the pace of transfer is too quick and the community is not ready to receive patients. If they had an advocate or someone to help them adapt then the situation might be quite different. A 'top down' policy of care in the community is insensitive to the practical realities on the ground. Therefore, 'bottom up' initiatives are required to make a reality of policy in diverse local settings.

It was suggested that it might be worth trying to define what categories of people should have case management and why they needed it. For instance, the severe head injuries project can be said to provide a paradigm of why case management is necessary. Such patients have no 'executive function' – that is, they cannot make decisions – and therefore need a case manager to help them. Another factor, perhaps the key determining criterion, is the extent to which patients deal with multiple agencies. Case management ought not to be necessary where only one agency is involved. In the area of disability, whether physical or otherwise, it is necessary for an individual to be a powerful social actor in order to negotiate a way through the service complex. The caseload of a case manager includes all types of people in terms of their capabilities, intelligence, experience or whatever.

The notion of 'need' gave rise to concern. Who defines need? As far as the Camden project is concerned, the guiding premise is simple: the service is available to anybody with a physical disability. Disabled persons choose whether or not to make use of the service. The team's task is to make sure services are available as necessary and to ensure that people know what is on offer. A variant of this approach is provided by the severe head injuries project where it is suggested that although clients may need support they may not know this at the time or seek to deny it. At the end of the day both projects arrived at the same endpoint – namely, an agreed contract – although in one case (Camden) this is negotiated between client and case manager whereas in the other (severe head injuries) there is rather more direction from the case manager.

It was suggested that some of the work done by case managers could be carried out by voluntary disablement associations set up by people with disabilities. These bodies often represent disabled people and assume an advocacy role on their behalf. They often serve as an initial point of contact. They might, however, experience difficulty in influencing statutory agencies' activities.

5 *In joint activity of the kind in evidence in the coordinator/case manager schemes the work is sensitive and political and requires particular skills for its successful execution.*

What range and type of skills are appropriate and what are the implications for staff training and development?

The skills and personalities of case managers are vitally important. An example of one initiative was given where two former district nurses are coordinators for a group of patients. Unfortunately, the nurses want to be nurses rather than coordinators and, as a result, are not particularly effective. They do not appear to have the right qualities for the task although the fact that they had been former nurses is not in itself of any significance. Case management demands initiative, a willingness and an ability to act, and good communication with all sorts of professionals. Moreover, whatever the professional training or qualifications of case managers these cease to be of primary importance in case management where independence from a particular disciplinary background is often required (although not in every instance as the Kent scheme shows). This is perceived to be a problem in the disability team where the therapists are employed as therapists and it has proved difficult for them to stand back and adopt a wider perspective.

It was suggested that case management could be taught and that a training programme ought to be established. Despite the importance of training, personality could not be dismissed as being of no significance. One of the most important prerequisites is that a case manager should really want to be a case manager and no longer want to be what they had been previously. If there is a latent desire to remain either a nurse, a social worker, a psychologist or whatever, then that person will probably not be an effective case manager. The position is different for a key worker who retains his or her professional identity while in effect 'doing an extra bit of coordination on the side'. Key workers also retain their professional identities as social workers, nurses or whatever. The orchestral analogy is useful in capturing the distinction between the two roles: the leader of the orchestra resembles a key worker while its conductor resembles a case manager.

6 *A degree of independence from the services being coordinated seems desirable if not essential. At the same time, complete neutrality and detachment would probably lessen the effectiveness of initiatives and their influence on statutory agencies. Some leverage or stake in the system is crucial.*

How can this be secured? By controlling budgets or through some other means?

The issue of independence was seen as critical. The notion of there being some kind of 'third force' in service delivery was thought to be essential. Mere coordination among existing service providers will not suffice. Ideally, case managers have to be quite separate from any professional hierarchy although, as the Kent scheme demonstrates, this is not always the case. The issue of funding is important in this respect because if schemes are to continue in being after the initial pump-priming period then a source of longer-term funding has to be identified. While the DHSS may be a potential source of support this cannot be relied upon in the longer term. More likely is some sort of joint funding for case management between health and social services.

Apart from financial independence there is also the need for independence to cross professional, service and agency boundaries and to think freely of possible solutions to problems. It is possible the two types of independence are linked. For the Camden project, and probably also the others, the issue of accountability has not hitherto been a major problem. The case managers are accountable primarily to clients. With funding from statutory agencies, it is conceivable that a steering group, or its equivalent, might wish to assume a more prominent and assertive role. It was agreed, too, that if any of the schemes become more permanent then representation from the client group with whom they are working would need to be sought.

The problem remains, however, that if case managers work for, and are funded by, health and social services there is a danger that they will be seen by clients as just part of the system. Having independent funding enables case managers to be answerable only to their clients. In the absence of independent funds then funding from several separate sources may provide sufficient independence. On the other hand, bodies like the Citizens Advice Bureaux are basically funded by local government yet retain their independence. Perhaps they provide a model to explore further.

7 *Successful coordinator/joint working arrangements are those for which service providers perceive a need. Even in those situations where patient/client advocacy may be uppermost, unless the support of service providers is forthcoming it seems improbable that coordinator/case manager schemes can survive for long without being marginalised and ultimately rendered redundant.*

How can support from services be enlisted if it is thought to be important?

Case management can be seen by service providers to be causing more problems rather than helping to solve existing ones. For instance, services might feel pressurised to provide facilities or do things which they have judged not to be a high priority. On the other hand, there are occasions where case management has led to alternative solutions being found which either utilise an agency's resources better or result in the use of other resources – perhaps those of another agency's. This flexibility in service response is a key feature of case management and is crucial in gaining the support of other services.

8 *Case manager schemes cannot be expected to compensate for basic resource shortages or for services under intense pressure. Solutions to such fundamental structural problems surely lie elsewhere. It is all too easy to invoke improved coordination as the cure to a whole range of such problems thereby diverting attention away from what in fact needs to be done.*

How can it be shown that coordination/case management is an appropriate response and that the problem to which it is addressed does not demand different solutions?

It is important to recognise the limits to case management. Much of the discussion centred, probably rightly so, on the advantages of case management and on the need to expand it. But case management is not a panacea – it cannot solve every problem. Its limits and the precise reasons for its introduction in a given situation need to be made explicit.

9 *Coordination and case management are widely perceived as a 'good thing'.*

What incentives may be introduced either to assist coordinators/case managers in their work or to encourage existing service providers themselves to coordinate without the intervention of a third force?

Probably altruism provides the principal incentive to case managers. But is a desire to operate in a better way to meet client needs sufficient? Will it result in sufficient recruits from established professional roles? Does the wider nature of the work offer sufficient appeal? It is claimed that proving that case management works will itself arouse interest and encourage people to train for it. Evaluation, then, is an important aspect of case management both in demonstrating its value and in encouraging its spread. The view was expressed that there seems little desire among existing service providers to act as case managers. Moreover, it is doubtful if they could perform such a role as it operates in the three schemes. On the other hand, the Kent scheme and its variants elsewhere demonstrate an enthusiasm among at least some social workers to function as case managers. This suggests that there is no one best way or single model and that local solutions need to emerge which fit local circumstances.

10 *The three pilot schemes are being funded for between two and three years. If successful – however success is defined and from whose perspective – there remains the issue of how innovative schemes can become part of mainstream provision.*

Is there a case for making the allocation of pump-priming funds conditional upon a commitment to take over funding of a project if, upon evaluation, it is shown to be successful?

See question 6 above. There was strong agreement for projects to become part of mainstream funding through health and/or local authorities provided safeguards could be built in to retain case managers' independence.

11 *Some case managers (not those described in the three schemes) exercise direct control of a budget which provides an incentive for improved client assessment and makes possible more creative responses to the individual needs of older people and their carers.*

What are the implications of not *having a budget?*

There was no strong feeling about case managers having budgets under their direct control. It was proposed that statutory agencies might contribute to a joint pool with a steering (or management) group established to which the individual case manager would be accountable. Whether delegating budgets to individuals would risk compromising the case manager's primary responsibility to the client was not explored, but given the tenor of the discussion it is likely that this would be seen as a possible danger.

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CHAPTER 6

Assessment and Conclusion

A fundamental point to emerge from the conference is the importance at the outset of being clear about terminology. The terms 'case manager', 'coordinator' and 'key worker' tend to be used interchangably and somewhat loosely. Yet, as was pointed out, they do not all describe the same activity. The main distinction is between case managers and key workers since coordination describes an aspect of functioning common to both. Unlike most key workers, case managers operate proactively and are usually with clients for a longer time, taking a more holistic view of their situation and needs. Case managers endeavour to blur their professional backgrounds and seek to secure their legitimacy through being accountable to clients and not to services, although this distinction is not always so clear cut and some case management schemes, like the Kent model, opt for accountability to services. So, even within case management, different models are available which have certain features in common but also reveal a number of significant variations in philosophy and approach.

A second key issue to emerge is the importance to all three schemes of client advocacy. It is a feature they share albeit in varying degrees. The different interpretations of advocacy probably reflect the different backgrounds of the case managers in the schemes and also the varying capabilities of the clients with whom the different case managers work. The most striking variations are apparent between the Camden project and the severe head injuries project and largely reflect the quite different clientele in each scheme.

A third key issue centres on the different levels on which case management can operate. For instance, for the disability team in Westminster and Kensington and Chelsea a strategic policy dimension is central to its work. The team attempts to get professionals *thinking* about disability in a more coordinated way while still retaining contact with individual clients referred to the team. In sharp contrast, in both the Camden project and the severe head injuries study, actual service coordination is important in terms of casework and in assessing client needs in conjunction with the client. In neither example is the case manager directly concerned with higher policy matters.

Fourth, case management appears to offer a range of benefits to clients, to service providers, and to the service system as a whole. The benefits will not always be distributed equally among the different interests although the Camden project case managers are of the opinion that this is not a problem since the benefits balance out over time. While this may be so, it seems important to sort out the aims and objectives of a project at the start in order to identify the likely benefits to emerge from it.

Fifth, the requisite skills for case management received attention. At issue is whether these skills are the product of a particular personality or whether they are something that can be taught and communicated. A combination of factors is at work, although it is clear that there is scope for developing training materials for case management.

Sixth, there was consensus concerning the importance of a genuine commitment to the principle of case management, and a recognition that it ought always to be an integral part of the service system rather than merely an 'add-on' which might not survive short-term funding.

Seventh, the matter of independence figured prominently in the discussions. All three schemes receive independent financial support from the King's Fund and in that sense can be said to be independent. But the problem remains of the relationship of case managers to other professionals, and of how they (the professionals) perceive the role of case managers and their authority. They may suspect the case manager of 'treading on their toes' or challenging their effectiveness. Despite claimed success in this area, it is nevertheless a highly sensitive matter.

Eighth, the matter of enabling successful pilot schemes to become part of mainstream provision once pump-priming funds are spent is of central concern to all three projects. The Camden team have given it much thought, possibly because their funding is closer to termination. From the King's Fund's point of view it is important to have an indication at an early stage of the prospects for continuation of an initiative after the initial funding period. The issue of funding is linked to that of independence, because if health and local authorities take over responsibility for funding there is a danger of jeopardising a scheme's independence.

Ninth, it was argued that case managers could either be generic or specialists. While there was consensus in favour of specialist case managers for particular client groups, a possible danger to guard against is the re-creation of boundary, and subsequent coordination, problems. Too many specialist case managers can give rise to problems of coordinating the case managers. Case management is about transcending boundaries and not about adding to them.

Finally, evaluating case manager initiatives is vital for policy and organisational learning. Two of the schemes are being evaluated; the evaluation of the Camden project is particularly comprehensive. Feedback is necessary for case managers but policy makers can also profit from it as well as the wider service community. Models of good practice require to be evaluated before they can be disseminated. Evaluation should embrace outcomes and processes. If learning is to occur and schemes are to be replicated, then it is not sufficient to know that something has worked. As important are the answers to such questions as *how* it worked and *why*. Crucial issues are the abilities and skills of case managers, their relationships with other professionals, clients and families, and the optimum size of their workloads. It is not possible, or even desirable, to be precise and mechanistic about such features in order that a manual can be produced, but there are issues about the extent of coverage of a case managed service, the time that needs to be devoted to each case and so on which might lend themselves to the production of a set of guidelines.

It was not the purpose of the conference, nor of this account based on it, to produce a set of guidelines but it is hoped that the material which has been presented contains sufficient pointers, themes and issues to allow a serious consideration of these.

APPENDIX

King Edward's Hospital Fund for London Conference on Coordinators, 11 November 1987

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Bridging the gap:

Case management and advocacy for people with physical handicaps

Case management is attracting considerable attention in Britain as a way of ensuring that individuals in need of care receive appropriate support. Following the Griffiths report, *Community Care: Agenda for Action*, interest is likely to grow. However, case management is not new; it has been established in North America for some time as a distinct discipline with a coherent theory and an accepted set of professional practices. But considerable confusion surrounds the concept and its application. Case management means a number of different ways of managing care, ranging from client advocacy on the one hand to managing services and resources on the other. These and other issues are explored in the context of three experimental projects supported by King Edward's Hospital Fund for London. Each project displays distinctive aspects of coordinated, or managed, care for people with physical handicaps. Too often, service providers, such as general practitioners and social workers, have little awareness of the potential of the services managed by others. They may also lack the power to mobilise this potential. The projects reported here try, in different ways, to address these problems. The book reviews a number of dimensions of managed care: the different types of case management; the relationship between case management and orthodox service responses; the issue of accountability in regard both to existing services and to users; and the skills and abilities which seem essential to successful case management and their training and staff development implications.

This book will be of particular interest to managers and providers of community care services, and to students of social policy administration and health care management.

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