The limits of altruism

ELDERLY MENTALLY INFIRM PEOPLE AS A TEST CASE FOR COLLABORATION

Tim Dartington

King Edward's Hospital Fund for London

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FOREWORD

In 1978 the Central Health Service Council and the Personal Social Services Council published the report of a study on *Collaboration in Community Care.* Following a conference on the relevance of this report for people and services in London, four bodies with interests in different aspects of collaboration set out to examine what practical action might be taken. Representatives from the King's Fund, the London Boroughs Training Committee, the London Voluntary Services Council and the National Institute of Social Work decided that some of the most pressing challenges to collaboration in community care arose in the support of elderly mentally frail people and they invited Age Concern Greater London to join them in a modest action research project. This was designed to assist the development of some examples of local collaboration and to increase understanding of the processes which either help or hinder their effectiveness. The King's Fund provided financial support. Tim Dartington carried out the field work during 1983–4. This paper provides the first published account of what was learnt.

How to achieve effective community care has of course been a continuing topic of public debate since the publication of *Collaboration in Community Care.* Tim Dartington's paper appears after the House of Commons Social Services Committee's own searching review of current experience which reinforces the general direction of policies seeking to ensure that vulnerable people are adequately supported in maintaining (or returning to) an ordinary community life, but underlines the extent to which practice has fallen short of expectations. As we also know from more local experience, the support of elderly mentally frail people can depend on informal carers who are grossly over-stretched and formally organised services, both voluntary and professional, which are desperately inadequate to meet growing demands. It is not surprising that hard-pressed individuals, however good their intentions, may encounter considerable difficulties in achieving successful collaboration with other people. Moreover, while there are some practical steps which can help to improve performance, we cannot expect quick solutions to many of their dilemmas.

Accordingly Tim Dartington does not offer easy answers. Rather his paper is a sensitive exploration of the social and psychological processes which influence collaborative work. Starting with the elderly person in need and his or her relationships with informal carers, the paper goes on to examine the strengths and weaknesses in much existing support as reflected in the experiences of both service providers and users. Efforts to do better will raise important questions not only for voluntary and professional workers on the front-line but for policy-makers and managers in the health, social services and voluntary agencies concerned with community care.

Different parts of the paper will no doubt seem particularly relevant to different sets of readers, but generally the text is designed to be 'worked at', not merely read. It offers an account of collaboration against which readers can assess their own experience; it is a stimulus for critical review and a resource for small-group discussion, for example in the context of training initiatives.

One such initiative is being mounted London-wide in 1985–6 by Advance, with support from the Mental Health Foundation. Tim Dartington is leading a programme of activities built on this research project, aiming to support participants in developing greater understanding and competence in working across professional and agency boundaries in the provision of community care.

The action research project reported in *The Limits of Altruism* was steered by a small group of senior officers from the sponsoring bodies. I had the privilege of chairing this steering group and my thanks are due to Malcolm Ford (LBTC), Tess Nind (LVSC and now Advance), Raymond Clarke, David Jones and Ian Sinclair (NISW), and Elizabeth Littlejohn (ACGL), who joined with me in working at better collaboration between our own organisations as the project developed. With our different roles and perspectives, we have different views about the issues raised in this paper, but we are all keen that they should be widely discussed. Accordingly, the King's Fund has undertaken publication.

David Towell
King's Fund College
December 1985

Part 1

INTRODUCTION TO THE PROJECT

For eighteen months a steering group from five agencies employed a researcher to study issues about collaborative working between individuals and agencies in meeting the needs of people at risk in the community.

Part 1 explains how the project came about, the reasons it developed as it did, and the kinds of questions it became necessary to ask. It also defines collaboration and explains why elderly mentally frail people are a test case for the effectiveness of community care.

The aim has been to find a useful way of thinking about working relations in providing community care. Community care, the official policy of successive governments since the inception of the welfare state, has done little to reduce the bias towards custodial care offered by health and social care agencies. Today, institutional care is seen as being increasingly unacceptable. It denies the rights of those being cared for, while its costs never cease to rise. Institutional care offers no hope of controlling the 'quiet epidemic' – the number of mentally frail people among our ever increasing dependent elderly population. Community care has never been more popular – but in an ambivalent way.

We may experience this ambivalence immediately at two levels. At the personal level we are full of admiration for the informal carer, struggling against impossible odds in conditions of Dickensian neglect in the effort to fulfil a sense of responsibility towards a demented elderly relative. At the same time, at a political level, this report is written at a time of particular sensitivity, when a director of social services in an inner London borough is predicting a 25 per cent cut in services involving the ending of home help services and closure of old peoples' homes – as a consequence of a political conflict between local and central government. A collapse of the sharing of responsibility at this level overshadows the potential for collaboration of those working with and around elderly people in the community. The mismatch between a generous personal response and more cautious political realities has the effect of hurting those we are wanting to help.

The background

This study of the processes of collaboration is itself the product of an attempt at collaborative work between five agencies in London. A small steering group from King Edward's Hospital Fund for London, the National Institute for Social Work, the London Boroughs' Training Committee, the London Voluntary Services Council and Age Concern Greater London, began to develop proposals for setting up a project supporting the local development of more effective approaches to meeting the needs of frail old people. In 1978 a report *Collaboration in Community Care* was published by the Central Health Services Council and the Personal Social Services Council. A joint study group of the two Councils had formulated proposals about the kind of services available within the community to many patients and clients who need both health care and social care. Their report stressed the importance of effective contact between different kinds of organizations and professions and confirmed the important part which the community itself plays in providing community care.

> If the major source of community care is the community itself, part of the task of statutory and voluntary agencies is to support its members by devoting adequate resources and staff time to the maintenance of existing resources in the community and the mobilization of new ones.[1]

The steering group identified the problems of frail old people, particularly those with mental infirmity, as the focus for further project work. They recognized that this was not a clearly bounded client group and it was partly because of problems of definition and allocation between services that effective collaboration in meeting the needs of these old people might be particularly difficult. In its proposals, the steering group was trying not to fall into the trap of professional and service demarcations of interest.

The project focus might be defined more agnostically therefore as being concerned with problem situations in which an old person is being identified by one or more parties as a source of difficulty attributed or attributable to mental infirmity. The sponsoring organizations recognized that to provide care within the community for any individual or group, regardless of age, raises problems for all concerned – professionals and non professionals, families, friends and neighbours. Even with an emphasis on elderly people, it should be possible to establish some principles of collaborative work that are of more general applicability.

At the beginning it was hoped to employ project staff who would be catalysts and linkage makers, offering independent support to local networks of people actively concerned to tackle existing problems and service provision for the frail elderly. Such support might range from one-off meetings on particular topics to continuing fieldwork spread over a year or more. Staff would encourage local workers to keep under continuous review the effectiveness of their own collaborative work. Where possible, they would work informally in putting people from one locality in contact with people from other localities where similar problems were being confronted, perhaps more successfully, or where illuminating comparisons might be possible. The common problems and solutions would be examined in multi-disciplinary workshops for the wider dissemination of particular local experiences. Four years later, it is still hoped that it will be possible to get funding to carry out work of this kind. The further exploratory research study that has been done in the meantime, may add weight – if that is really needed, when there is so much talk of the importance of collaboration in community care – to arguments supportive of such an initiative.

The steering group ran into difficulties about funding a project about collaboration because collaborative work by its nature does not fit easily to the needs of funding bodies, who, like service agencies, work to quite strict criteria about what is or is not a priority or central concern for them.

The generic nature of the work suggested that specialist funders may be less able to support this work than, say, the DHSS itself, but the DHSS also has its own priorities.

The steering group was able to attract funding from one of the sponsoring organizations, the King Edward's Hospital Fund for London. The decision was made to go ahead with an exploratory study, giving priority to three aims:

1. to encourage improvements in collaboration among statutory and voluntary agencies in ways which take full account of the perspectives of clients and the nature of informal contributors to community care;
2. to provide advice and support to workers in a limited number of localities where multi-agency professional efforts are being made to tackle problems in the delivery of health and welfare services; and, especially,
3. to use this work as a means to identify good practices in collaboration in difficult 'interface areas' and the conditions necessary for such practices to be implemented.

The researcher's task has been to make contact with local projects and people, both to learn from them how collaboration around elderly people works in their situation and, where possible, to assist them in their own understanding of the processes involved. This 'enlightenment model' of social research – with the aim of finding formulations of principle that are useful to practitioners – has advantages, both to do with economies of scale and also in looking for underlying dynamics in the relatedness of those working with the demands of highly dependent people in society. It may then be possible to look at the processes by which collaborative working can be achieved, as those working with and caring for elderly mentally frail people explore the boundaries of their mutual concern.

It is not in itself enough to give rational accounts of the advantages of inter-disciplinary cooperation. Examples of good practice do not help in themselves if people react by a) saying that is what they are doing anyway, while b) carrying on in the same old way. So we are not asking for examples of good practice, until we have established what may be the principles of practice. Case studies – different in different circumstances – may then be the best way forward, as those closely involved evaluate their own struggles to offer pragmatic solutions to intractible problems. Two of the sponsoring organizations, the London Voluntary Service Council and the London Boroughs' Training Committee, have developed training programmes to help people evaluate their own projects in this way and workers in the Neighbourhood Care Action Programme in Advance have published a manual for community groups wanting to look at methods of evaluating their work.[2]

In sum, this study is an exploration of the limits of altruism, where the usual gratifications in caring for others do not seem to be present. Some professionals, psychiatrists, geriatricians, psychologists, social workers and others, find ways of extending their expertise to work with this most recalcitrant group of patients and clients. Others feel that their skills are undermined and emphasize that there are other demands on them. The degeneration of extreme old age and debility is an exercise in loyalty for those who have worked and lived with old people in other times. Simone de Beauvoir wrote a classic study of old age and has recently published her own account of the old age of Jean-Paul Sartre.[3] It is the kind of account that attracts accusations of bad taste. We prefer perhaps to emphasize the achievements of old age, for example as Alex Comfort has done.[4] We admire artists, musicians, religious leaders and politicians – and others at the height of their powers in old age – but we are testing the limits of altruism, when we are thinking of those who do not seem to have anything left to give. Informal carers have a loyalty to the past. Professional carers may find a way of meeting their own need to be useful in the exercise of their skills and the management of their resources. We know that elderly people can become isolated socially, economically, geographically – and finally, mentally. Their relationships become limited. The more dependent they become, the less able they are to negotiate the kind of care that they need. Without an element of reciprocity, the care that they get may be minimal, grudging and even cruel in its effects.

Finding an appropriate methodology

If one believes that we should have the social organization necessary to cope with all sorts of problems, however intractible, in society, then the inadequacies of community care are frustrating and difficult to understand. What if we try to understand individuals and the agencies in which they work equally as open systems relating to their environment, so that behaviour is seen to be a product of both internal and external forces? The behaviour of individuals and larger systems may both be expected to have conscious and unconscious elements, so that we act differently from what would seem to be our intentions. In a previous study of the distribution of attitudes around disabled people, *A Life Together*, this approach was helpful in looking at discrepancies in the provision of services for physically dependent people in both institutional and community care.[5] Several observers inside and outside the DHSS have drawn attention to the discrepancy between the reality and the rhetoric about community care of elderly people. This study is an attempt to understand the discrepancies, so that those who want to understand them may be helped in looking at ways of making their working practice more effective.

It is not concerned with possible answers to a problem but with the difficulty of asking the questions. Everyone talks about collaboration as a good idea while protesting that it does not happen. There is an urgent need to understand more about this gap between reality and the ideal; otherwise we should discipline ourselves and stop talking about collaboration altogether. How is it that collaboration is such a good idea if our experience is that it is unworkable?

It is necessary to look at the way people of different agencies, experience, resources, work together, and the methodology used was itself part of this process of working together. A researcher develops various relationships with social workers, health workers, voluntary workers and informal carers. These relationships range from the informative (one-way) to the participative (where each side is learning) and so reflect also the kinds of involvement that workers may want to have with each other.

In the informative relationship, the researcher goes along and asks his questions. This takes up other people's time and they wonder what the use is of it all. They may agree to cooperate; they may be persuaded of that by those in authority over them; otherwise they may simply find the research interview a welcome relief from the immediate pressures of their work. Finally, they may come to think that the relationship is reciprocal after all and that a useful statement about their working lives will result, although what they receive will probably be different from what they expect. At best, the outcome is uncertain.

The participative relationship is different as the transaction is always intended to be mutual. Research interviews could be collaborative in this way, examining the context within which people worked and the ideas that informed their actions. Such dialogues allow for the generation of data between researcher and respondent and shared hypotheses about the nature of collaboration.

Contacts were made – usually through the networks available to the sponsoring organizations – with workers in health and social services and the voluntary sector in a broad sweep of London boroughs from Brent and Enfield in the north, through Islington, Tower Hamlets, Newham, Greenwich, Lewisham, Southwark and Westminster. In addition, it was possible to make visits to particular projects in other boroughs, for example visiting community psychiatric nursing services in Croydon and the home care service run by social services in Waltham Forest. Age Concern workers have been significant respondents, where their roles have allowed them to exercise leadership in collaborative work.

In the course of the project, it has been possible to explore the issues raised in another form, that of the workshop. There were several opportunities to work with groups of 20–40 people drawn in more or less equal proportions from health and social services and the voluntary sector in different boroughs and health districts and to test these ideas further in discussion groups at a number of day conferences, whose organizers have included Age Concern Greater London and the Kings Fund Centre. A specially useful event has been a monthly workshop at the London Voluntary Service Council for those working to support the carers of elderly mentally infirm people. Here we have seen participative relationships at work, as people report on working practice, contribute ideas, and develop proposals for further action.

Two kinds of resource available to elderly mentally frail people in the community emerged as the focus for discussion about the potential and the actuality of collaboration.

1. The support of informal carers – there is a demonstrable need for consultancy and support to workers both in voluntary and statutory services, who are thinking of setting up and managing relative support groups, encouraging self help and advocacy on behalf of carers and their elderly people, and developing more effective working relationships between the informal and formal systems of care. Inevitably these issues bring all concerned up against the problems of collaboration both in terms of resources and support.
2. Day care for the elderly mentally infirm – there are examples of collaboration between the voluntary sector and social services in the provision of lunch clubs and day centres, often emphasizing reality orientation and reminiscence work, and relief in domiciliary care through extensions of the care attendance schemes first developed around the needs of disabled people.

Definitions of collaborative working

There is something about the concept of collaboration that encourages idealism, that is not always realised.

> Collaboration is an essential part of our work.
>
> It would be madness if we were not collaborating with the other services.

Introducing the subject to a wide range of people in the health and social services, one came to expect a general if vague acknowledgement of importance of collaboration, as if it were only stating the obvious – and what was the fuss about anyway?

> We refer clients to the geriatric visitors. They are pretty good really.

In common usage collaboration can mean little more than what happens when one agency accepts a referral from another. It also implies that if the other agency does not accept the referral, it is not collaborating. This kind of definition is one-sided. It is describing ordinary working practice, where one is pleased with the outcome.

In discussions and workshops, it has been possible to look for more meaning than that. A dismissive description of collaboration – 'We do it all the time' – may even be defensive, avoiding the need to look at the way one working practice impinges on another.

The document *Collaboration in Community Care* reported on a questionnaire sent to health authorities and social services departments.[1] Respondents reported particular examples of collaboration: structured case conferences, informal case conferences, formal referrals, informal referrals, teamwork, attachment of social service personnel to the health services, attachment of health personnel to social services. These are mechanisms which may contribute to collaboration and may or may not be effective. We have all sat in case conferences and similar meetings where their purpose is undermined by the clash of interests. Referrals can be a way of dumping people. Teamwork can be a label attached to authoritarian rule. The attachment of a worker to another service has often been a very isolating experience. The mechanisms are there to be used but if we are going to look at the process of collaboration, we need to have a clear definition of what we are trying to do.

In the study we have been asking how appreciation of a common task may mean that people and agencies mutually change their way of working with each other. We have been looking at collaboration in working relations as an opportunity for innovation and change.

Any organization has to relate to its environment. It is an important leadership function to try and manage the relationship between the organization and others with whom it is working. We also know the difficulties of representation, worrying whether others are representing us properly or whether we really have the authority to represent them. Mechanisms for working relationships are the ways in which the organization seeks to protect its own interest while working with others.

Collaboration – working together well – is thus a process of negotiation, of opening up one's own boundaries in getting others to do what one wants.

In *Voluntary and statutory collaboration*, Diana Leat and her colleagues stated clearly both how important, and uncomfortable, it was to be an intermediary – like a council of voluntary service – which is trying to make the pluralist provision of welfare services work.

> Problems around representation crop up again and again. These range from the defensiveness of councillors over their representative role to ambiguity from both the statutory and voluntary sectors concerning the representatives of voluntary participants. The importance of statutory attitudes and structures is highlighted – effects of commitment to the appearance but not the practice of participation, the constraints of timetables, and statutory hierarchies. The statutory-voluntary clash of interests – over money, time and power – is also illustrated. The problem of establishing consensus is another recurrent theme. The CVS as middle man caught between the sometimes incompatible expectations and demands of its various statutory and voluntary constituents is clearly illustrated. What also becomes clear is that the viability of the intermediary role is largely dependent upon the integration of the local voluntary sector.[6]

Freely admitting that collaboration is difficult is the starting point for trying to make it work. The subtitle of the NCVO report quoted above is *Rhetoric or reality?*

The Health Advisory Service document on developing services for mental illness in old age, *The rising tide*, talks of working partnerships.

> Specialist services for the psychiatry of old age do not stand alone. They need regular working partnership with a number of other departments and organizations in the health service, local authority services and the voluntary sector. Many of the complaints and irritations that arise around the delivery of services, especially for the confused elderly, are in the boundary areas between departments, in the overlap of interlocking circles. It is distressing to hear, as is the case in some districts, of the lack of communication, for example between psychiatrists and geriatricians, over shared problems. In others, social workers may complain of

> the difficulty of obtaining advice within old peoples' homes or the psychiatrist may point to capable old people who remain in hospital for want of community support.[7]

The distinctions that we make between different kinds of care do not just get people muddled, because they sometimes get them wrong: they are artificial and so we always get them wrong. The Secretary of State for Social Services has made the artificiality of distinctions an item for collaboration.

> In discussing the need for hospital care, one at once runs into another boundary problem – that is, the boundary between hospital and Part 3 accommodation. There can be no set rule. I welcome initiatives in which health staff are assisting local authority staff in residential homes to cope with a wider range of problems than they have traditionally managed....[8]

It is part of the rhetoric of conferences that the boundaries between the statutory and the voluntary sectors will always be variable and that 'connections are more important than boundaries'.[9]

The distinctions become even more difficult to maintain in looking at the limits of informal care. David Gilroy has tried to look at the reality behind the rhetoric.

> It is probably common ground that provision made by SSD's and formally constituted voluntary organizations is not 'informal'. But what about the 'extra' work for their 'clients' outside their normal working hours? Where do neighbourhood care schemes or mutual aid groups fit in? Are the tasks undertaken by 'volunteers' best considered as part of the 'informal sector' and if not, where does one type of activity start and the other stop?[10]

The aim in collaboration is generally assumed to be better practice, better delivery of services to the client group. We talk of more efficient use of resources: but things are often seen differently by managers and clients. Sometimes workers try to cope with the difference, for example where the voluntary 'extra' work done by some home helps bridges the gap between the expectations of the agency and the needs of the client.

Transport schemes are often criticized, because they are moving clients and patients from one system of care to another and so are subject to two sets of expectations. Transport problems can be a way of maintaining the distance between two agencies and between the agencies and their clients.

It is necessary to distinguish collaboration from cooperation. Liaison and cooperation are ways in which different agencies can help each other to be efficient on their own terms. Collaboration implies something more, working together to achieve something that none of the agencies could do on their own. So each agency may be seen to be managing its own resources while contributing to a temporary system to which it lends resources (Figure 1).

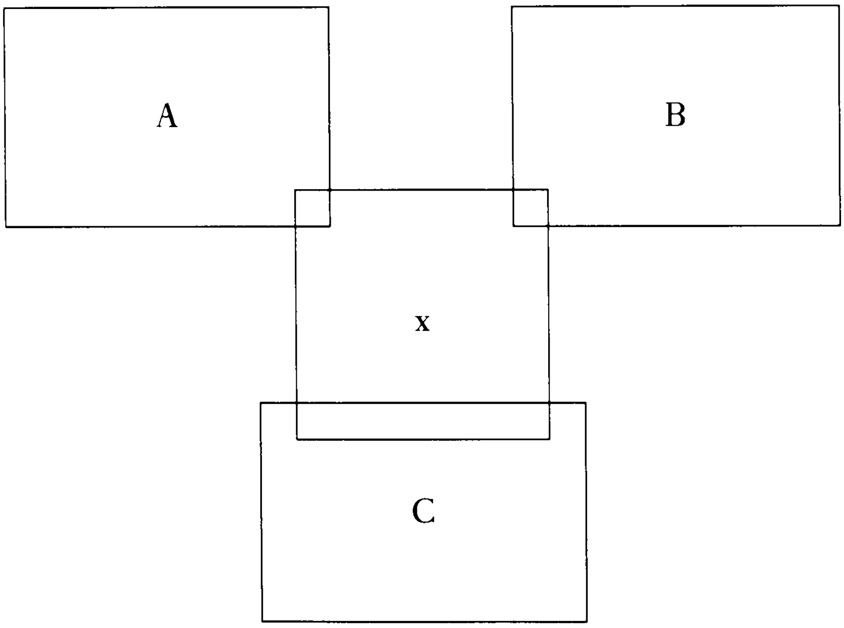

Figure 1: The temporary task system (x) draws in different proportions from agencies A, B and C. It is different from any one agency, and the agencies cannot independently carry out the different bits of its work.

Collaboration is thus more than a palliative, and it engages professionals in a genuine extension of their role. It is a creative activity, risky because it is not defensive. At the same time, it is worth remembering that the wartime definition of collaboration meant working with the enemy.

The elderly mentally infirm: a test case for collaboration

The elderly mentally infirm represent the unacceptable face of ageing.

> I am an old woman now
> And Nature is cruel.
> It is her jest to make
> Old age look like a fool.[11]

We have taken the example of the 'elderly mentally infirm' in looking at collaboration in community care. As Alison Norman has argued, we should not look at their need in isolation from other elderly, but we should also not deny the particular difficulties faced by those trying to respond to the needs of people who are not only old but mentally confused.[12] It is difficult to know how to respond to dependency without making it worse. Anyone who has visited the back ward of a psychiatric hospital, where elderly patients in advanced stages of dementia are living together without dignity or hope, must feel a mixture of shame and horror at this vision of the seventh age of man – sans everything. *Sans everything* was itself the title of an influential report on the plight of elderly people in institutions.[13] Without a social context the meaninglessness of these lives becomes overwhelming.

By 1991 there may need to be 20,000 hospital beds for elderly people suffering from dementia. That figure will be greater still, if social factors, isolation or the breakdown of family care, increase the demand for hospitalization. But it is also commonly recognized that the 'worst' patients are not necessarily always those who are in hospital. Also those who are severely demented come from a very much larger number of elderly people – measured in hundreds of thousands – suffering from some degree of dementia and memory loss.

Hospitalization is not a solution, except for a very few people. On other humanitarian and psychological as well as economic grounds, community care will have to cope with a large number of people (though still a very small minority in society as a whole), who are dependent on others in their social relations, their economic status and, by the nature of their debility, decreasingly able to represent their own interests, aspirations, needs, in relation to those around them, however well meaning they are.

This is a test case for collaboration in community care. In our health and social work provision we have attempted to specialize as best we can and then in compensation have created generalist resources. There are social workers with an interest in the elderly working in generalist teams, whose professional priorities may be families and children. To work exclusively with elderly mentally infirm people is unsatisfactory if the worker achieves little and experiences little in the way of thanks or reward. It is necessary to find a social context within which mental illness in old age does not have to be treated in isolation.

Mental frailty in the elderly offers a particular challenge to the values and social structures of an advanced industrial society, which discriminates in favour of the employed against the unemployed, men against women, the prosperous against the poor.

Researchers and others are in a strangely ritualistic position, stating the obvious about care of the elderly. Whether we go to conferences or watch television programmes, what we expect to hear is much the same: that the elderly are getting more and more numerous; and therefore, they get to be very expensive; families are going to have to do most of the caring.

It is ironic that the increasing recognition of the importance of the family in community care comes at a time when the family is unable to live up to this image of a cohesive and reliable source of help. When we talk about the population explosion of elderly people, we are not talking about people simply of pensionable age. There are about eight million pensioners in England and Wales, a number that is likely to stay constant until the end of the century. But within the eight million, there will be a shift from the younger, fitter people, who make up many of the natural carers, to the older, frailer people. It has been estimated that one-fifth of the elderly over-85s now living at home are already bed-fast or house-bound.[14]

Some writers now distinguish between 'young old' and 'old old'. At the moment the description 'pensioner' is generally accepted and seems to have taken over from the false-sounding 'senior citizen' – citizenship not being a role that is particularly well understood in our society.

It might be a sign of a healthy society if people could be old after they were no longer middle aged, but now the denial of age is evidence of well-being. 'I am a hundred years young,' says the old woman, and we laugh and admire her spirit.

What is wrong with being old? There are naturally fears of debility and disease associated with increasing age, but that is not all. There is also social redundancy.

> Our society has no positive conception of a role for old age either in the community or in the life of the individual ... Ask most old people what they think old age is for and they reply with a blank stare. After a lifetime of work and rearing families they continue to feel they should be some use to somebody but they are largely condemned to passivity ... Without a role the old even condemn themselves as useless.[15]

We may all need to avoid linguistic traps in thinking about the care of the elderly. The elderly have survived or avoided the kinds of accidents and diseases that kill younger people, but by thinking of them as a separate category this ability to survive has been turned into a disadvantage. This leads to pussyfooting around with names and definitions. Originally, senile commonly meant old, but by association with dementia, it has become a term of abuse and unacceptable. 'Old' is in danger of going the same way. We try to be precise with terms like elderly mentally infirm (emi) but whatever term we use is likely to have its critics. The Health Advisory Service document *The rising tide* prefers 'mental illness in old age' or 'elderly mentally ill'.

People of retirement age do not like to be included in a category of elderly at all. Later they find they are too old or not old enough, too frail or not frail enough, neither a geriatric nor a psychiatric problem; and care belongs to neither family nor state.

In 1983, the DHSS organized a national conference on Supporting the Informal Carers. The Under-Secretary of State who gave the opening address said that the conference was to 'highlight the needs of informal carers and ways of meeting their needs'.

> There are far too many anecdotes of carers being ignored or of services being entirely oblivious to the carer's existence . . . Carers need to know that they are valued. Carers cannot help but be aware of the importance of their work but if no-one else seems to notice, doubt and bitterness can set in.[16]

The Minister had already been pressed about the invalid care allowance.

> The government is well aware of the case put forward to spend more, for instance, for an extension of invalid care allowance to married women. Leaving aside any social arguments that may be put on either side, such an extension of invalid care allowance would cost an estimated sixty million pounds a year, even allowing for savings on other benefits. It could therefore only be seen as one of many competing claims to be considered in the context of deciding priorities for public expenditure as a whole.

Enid Levin reported 41 per cent of the carers in the recent National Institute for Social Work study were the wives or husbands of the supported person.[17]

The political response draws on an idealistic mode of collaboration, with an appeal to supposedly Victorian values of family life and caring before there was a need for a welfare state.

At the same conference, a director of social services, Kenneth Young, described some of the realities of family life.

> The 'typical' household of 2 children and 2 adults where the father works and the mother stays at home with her children has, as we all appreciate, long been the focus of British family policy. However, such a family now represents only 15% of all households in the United Kingdom.[16]

After referring to marital break-up, child rearing outside marriage and equal employment opportunities for women, Kenneth Young argued that social policy is working towards an unrealistic family model of care.

> The attention now given to the development of a family policy asserts the importance of the domestic caring roles of women. Social planning over the decade is likely to empha-

> size such 'domestication' of women, both to provide the 'voluntary' resources necessary to replace state health and welfare provision for the physically dependent, both children and old people, and to reduce competition within the labour market for few jobs whilst also reducing demand for social security benefits available to those actively seeking work.

Politicians are among the most loyal supporters of the concept of community care, but it is important not to underestimate either the complexity or the social and economic costs.

> The right policy is to provide what people need at the time they need it. It is greatly preferable to dealing solely in expensive packets of long-stay in-patient care for which waiting lists build up while waiting patients deteriorate irreversibly. It may well be that this change which I am advocating from crisis-led care to planned co-ordination may mean some extra demand on resources over the period when the change takes place.[8]

Community care is being promoted for continuing care of very dependent people, because the health and social services themselves cannot cope. In the way that people have traditionally looked to the authority of the professions and the dependency of the institutions, now there is a dramatic reversal. Policy-makers and practitioners are looking to the people to take over a responsibility that the health and social services cannot otherwise carry out.

Who will mother Mother?

At this point everyone starts talking knowledgeably about community care. Part 2 looks at the process of collaboration in community care as a further elaboration of the dynamics of family and informal care.

Part 2

COMMUNITY CARE: MANAGING THE CONFLICT OF INTERESTS AMONG THE VARIOUS PARTIES AROUND AN OLDER PERSON AT RISK AT HOME

Introduction

The phrase 'community care' implies diffused containment of a person living among other people. Where it is intended to mean care by the community and not care *in* the community – mini-institutionalisation – we have to ask how this diffused containment can be managed. Who is to be responsible for an elderly person suffering intellectual impairment living at home at some personal risk, causing worry and disruption and perhaps some risk to others? The various parties involved have their own views about areas of responsibility, which will differ from case to case.

Sharing responsibility for care of the frail elderly is subject to a conflict of interests. Each of the interested parties has its own perception of what it is good at – and what it ought to be doing – and often does not see caring for the frail elderly as its *primary* purpose. If social workers think their skills are best used on case-work with families with children; if a nurse gets job satisfaction from comforting the sick; if medical resources are concentrated where they can produce the most dramatic results; or the family is seen as a social and economic unit devoted to bringing up of children; then social workers, nurses, doctors and families have to find other reasons for wanting to choose to look after elderly mentally frail people.

Informal carers are the main protagonists of the invisible care on which elderly mentally frail people depend, and it is first necessary to look at the expectations they have of themselves and others have of them. Health and social services make clinical and professional decisions which also involve them in arbitrating ethical issues about the sharing of responsibility. Professionals have developed projects to bridge the gap to informal care and voluntary organizations have made a particular contribution in the development of day care services. In such ways we are struggling towards an integration of professional and informal care. Our ambivalent expectations of medical leadership (both in the community and in hospitals) will be examined before, finally, we look at ways that familial conflict is replicated in the networks of care around elderly people at risk living at home.

Informal carers – the main protagonists of 'invisible' care

Family carers – and, more widely, neighbours and other informal carers – are increasingly recognised as carrying out a major part of the effective care of elderly mentally frail people. The professional agencies have had the answer to their problem in front of them all the time and so they now try to do more to support family care. One factor to the advantage of family and friends may be so obvious that it is overlooked; the motivation of carers and the rewards are very different from those of workers. In a study of neighbourly helping of the elderly, Diana Leat emphasized the distinction between reciprocal and non-reciprocal relationships. She described the complexity of reciprocity and argued that we have to try to understand what is going on if research into informal care is not to be misleading.

> Reciprocal care and support relationships were frequently uncovered after we had been told by the respondent that no help was received from neighbours ... In general, people did not respond to questions about help from neighbours, and information about care and support networks only emerged in the course of often lengthy interviews about everyday life and general relationships with family, friends and people living nearby.[18]

People often do not like to ask for help, when asking implies dependency. But there may be a history of family or neighbourhood support, which protects the elderly person from the supposed ill effects of 'help'. Leat drew attention to the working of delayed reciprocity.

> Current care may be seen as an exchange or return for help received many years ago or for help received from some other member of the present recipient's family.

Care is distantly related to the concept of justice: it also includes elements of reparation, of support for the weak, and of moral judgement. Perhaps this is why we want care, like justice, not only to be done but to be seen to be done. Failure to care, whether by ourselves or others, makes us feel angry and guilty. However, the elderly mentally frail are not the most publicly disadvantaged people in the community. They are isolated individuals, living alone at home or with a caring family to protect them from the outside world. If they are given to wandering, or showing other signs that they are at risk in the community, they stimulate demands for institutional care. Often their carers are intent on distracting other people from the fact that they are at risk; and the survival instinct of elderly people – not only the mentally frail – sometimes makes them very secretive about their affairs.

Enid Levin has drawn attention to the social and psychological costs of this commitment by carers.

> About one third of the supporters reported a number of symptoms of acute stress sufficient to suggest a need for psychiatric attention.[17]

When we asked informal carers about collaboration, they talked about principle rather than practice.

> When I came out of the group (of informal carers) I felt like a wet rag. You have to resist the temptation to tell the people that there is nothing that can be done. They are right to be angry.

> It's all very well for you to tell me that I should get out to a group. I haven't been able to get out for three years. [Nevertheless, this carer was at the meeting because day care facilities were provided. But she was unwavering in her sense of isolation.]

> There's nothing you can do to help. I've had to do it all myself.

The contribution that this last carer made to a discussion where facilities were being planned at local level aroused powerful feelings of sympathy: but the intransigence expressed in denying any potential for change was also frustrating and, ultimately, dispiriting for the others. Physical and psychological constraints in the individual became difficult to disentangle.

> Someone came to see me – a social worker as it happens – her widowed mother-in-law was sitting at home and seemed not to be having any grief reaction. The daughter-in-law went to the GP for advice and what do you think happened? He sent the old woman away for physical tests and they found there was nothing wrong with her. And he sent the younger woman to the psychiatrist!

It was as if one was too young to have physical symptoms and the other too old for counselling.

More is being heard from 'invisible' carers at conferences. I went to a public meeting where carers were able to confront the health and social services and demonstrated their new authority – an authority derived from their experiences being recognised as valid by health and social workers.

A carer described how she heard that her husband had pre-senile dementia in a five-minute consultation with a GP. She went to the social services and was 'passed from pillar to post'. She got support in the end from the local Age Concern. Another carer with 13 years' experience of looking after her father was herself elderly. When she went into hospital there was short-term residential care for him, but then he was returned to her care. The house smelt of his urine and he had not washed for months. At the meeting it was established that no home help had been offered. Social workers, said one of those present, were not trained in assessment and often were unable to persuade the GP to refer a patient for assessment – and this was an area where there was no psychogeriatrician. Another carer had been helped by the GP and her father went to a day centre, where he was bathed and cared for, and he was seen by a geriatrician and finally admitted to hospital. When carers give voice to their experience in this way, the representatives of the health and social services realise how these services can seem like a lottery to those most in need of them.

With a development worker from Age Concern Greater London I organised a one-day workshop on support groups for caring relatives. Workers in the health and social services and in the voluntary sector examined how they might develop support groups for caring relatives as a complement to the practical assistance given by the statutory health and social services.

The workshop drew on the experience of twenty-five people from a variety of backgrounds. They included social workers and community workers from social services and voluntary organisations, and health workers from hospitals and day hospitals. It provided an opportunity to develop a supportive network for those who wanted to develop their ideas about working with informal carers, and put them into practice.

The value of support groups for relatives was seen to be in giving them an opportunity for self help by meeting in small informal groups. In this way they can share their common knowledge and experience and gain emotional support from each other at a time of stress. This is of value in confronting the sense of ignorance, helplessness and, sometimes, depression experienced by many relatives. Membership of such a group can enable carers to carry on caring and give them a voice in the planning of the care, whether their confused elderly person continues to live at home, goes into a hospital, or into local authority residential care.

Support groups are also important to professionals whose job is to work with the elderly. The professionals take up a facilitating role, allowing the relatives to use their own skills and offering them support which does not take them away from their skills. This is very different from a non-collaborative relationship, where informal carers have to fit in with the way professionals manage and control their resources.

The workshop was an opportunity for professionals to take a multi-disciplinary approach to their relationships with informal carers. If caring relatives are seen as people to be worked around, or even a nuisance to be excluded rather than a vital resource, it may be useful to think out a different relationship from first principles. Simply to attempt to impose – even implicitly – a way of working would replicate the imposition of professional attitudes on informal carers. Instead, the multi-disciplinary approach of the workshop was intended to replicate the self-help model, where the participants developed a new confidence in their own expertise.

In planning the event, it was thought that the discussions might usefully lead from practical concerns – the visible contribution of health and social services – to confronting the emotional needs of carers. Given the opportunity, carers might express more freely the kind of feelings that professional workers had to contain, or even deny, in their own organisations. It was found to be difficult to sustain the distinction between emotional and practical support. Was it right to assume that carers would want practical help and advice first, and later, when they had got to trust each other, share some of their feelings? As some of those who already worked with carers knew, it might happen that a relative would grab the first opportunity to pour out emotions that had been held in check.

These workshop discussions were an opportunity to look at the needs of carers as the professional workers understood them, but from the perspective of the carers. The emotional content of caring was seen to be a very high priority. This led the professional participants to look at how they themselves, and others in their position, might relate to carers. Some only saw carers when they were no longer able to cope, and so had little experience of how relatives put up with the stress of caring over long and indefinite periods, often with very little support. Others knew how defensive they were, laying down the ground rules, and realising that their perceptions of clients and patients were influenced by the resources they might, or might not, have. Group work with relatives was an opportunity to develop a different kind of relationship with carers and, through them, with elderly mentally frail people. However, the workers were also anxious about how they would be able to cope with this challenge.

The workers wanted to give due recognition to the role of the carer, talking of the lack of status attached to being a carer, and how necessary it was to give reassurance and reinforcement to people, who have doubts about what they are doing or are subject to conflict within the family and feel guilty towards their elderly relatives. One group emphasised the stigmas associated with mental illness in some parts of the Asian community, where a mentally ill patient in the family may undermine the opportunities for marriageable daughters. In any culture, the family can fear that mental illness is hereditary or contagious, and its members feel that, in some undefinable sense, they are at fault.

Workers had little difficulty in identifying with the experiences of carers. They too experienced being undervalued while being overworked, resenting the impossible demands being made of them and yet feeling guilty for not doing more. This idea was taken further – that carers might develop the kinds of defences that traditionally workers have used. Carers may need the opportunity to manipulate others, as social workers and health workers do, to compensate for the way their elderly relatives manipulate them.

The workers discussed ways in which informal carers relate to different agencies. In some ways they are more generic minded than the professionals and may see everything as simply coming from 'the welfare'. But families also try to come to their own understanding of the distinctions between health and social services. At a hospital they will talk about incontinence but not about leaving on the gas taps. The irony, of course, is that worry about the gas taps may be more likely to get supportive action from the statutory services than talk about incontinence.

Participants were careful to distinguish support for families from the 'training' of relatives – which might be manipulative and cause them to avoid their own responsibilities. Even the giving of information was seen as secondary to the work of supporting the role of carer, so that people might be effective in their own right. There was a fear that the concept of relatives' support groups might be used by agencies to cover for their own lack of resources – an unspoken assumption that carers were being recruited to work for ends determined by the social services. In resisting a manipulative stance, professionals were aware of their own deficiencies and their talk of training was about training for themselves. This was evidence of new respect for the informal carers.

Although relatives' groups were thought to be self-help groups, this did not mean that workers in the health and social services had no useful role in relation to them. While professionals were anxious that their skills should not overwhelm or threaten the ability of carers to determine their own needs, in fact there would be little mutual support initiated or sustained among informal carers without the intervention of professionals with frail elderly people.

Some participants may have felt less confidence than they would like about whether they had a useful role with informal carers and the relatives of elderly people. In recognising the authority of carers, it was possible to deny one's own skills.

It was accepted that a relatives' support group should have two objectives: a) to enable participants to share their common knowledge and experience; and b) to combat the profound sense of ignorance, helplessness and sometimes depression that was reported by carers. The groups would hand back to informal carers at least some sense of control of their situation. Once the conditions had been provided where people could meet safely and share seriously their common concerns, the group itself would then develop its own life and way of working.

The importance of relatives' support groups is that they legitimise the experiences of carers by breaking down their isolation. By sharing their common concerns they find a way to examine the meaning of their caring which others then confirm. Behaviour that might seem to be pathological comes to be seen as normal in the role of carer.

I met a relatives' support group, which came together in an old peoples' home, so that carers could, if they wanted, bring their elderly relative to be looked after during the meeting. The group was arranged by a voluntary organisation worker, who had also involved a social worker from the local authority. The people came as a result of an advertisement in the local paper. There were four carers, all women, and three of them were coming to the group for the first time.

Each carer told her story almost without interruption. They addressed themselves mainly to the person they identified as the 'group leader', the worker from the voluntary organisation. The social worker contributed some factual comments about day-care provision.

Mrs R described her mother as suffering the 'early stages' of pre-senile dementia. This was the diagnosis that she had heard from the psychiatrist. Her mother lived alone and she visited her every day. There was another daughter but she lived fifteen miles away.

Mrs R talked of feeling guilty that she was not doing enough – and also worrying that she was being overprotective. In such ways she seemed to be showing the kinds of insight that one might associate with social workers. She also showed herself to be well organised in her daily living. She had contact with a social worker and also with the psychiatrist who was recommending that her mother should be going into Part 3 accommodation.

The mother would not consider even going for day care, let alone what she called 'Stage 3'.

Mrs R had come up with a temporary expedient, an imaginative use of resources available to her. There used to be a home help, who for some reason had not continued to come. Her son's girl-friend had gone as 'lodger' in her mother's house. However, her mother did not understand that the lodger was paying her way.

At this point the social worker was able to intervene, challenging the seeming passivity of clients about the non-appearance of services. He explained that home helps were not always told of circumstances of clients.

Mrs W lived locally but her parents lived thirty miles outside London. She talked of her mother as being the problem. She wandered off and had lost two bags of shopping. Mrs W's father looked after her as best he could but he was now eighty years old. A place had been found for the old woman in a hospital but he would have to drive ten miles to visit her there and so was reluctant to agree to this plan.

The group leader offered direct help, arranging to find out what services there might be in the area where Mrs W's parents lived. It was important that she be aware of any alternative care possibilities. Mrs W accepted this offer in a matter-of-fact way. She went on to talk more of her own needs, her own sense of ignorance. She wanted to know more factual things about what she hesitatingly called mental problems. She gave an impression of not being happy with things she could not understand. She described herself as a practical sort of person and talked appreciatively of an aunt – you could phone her and go and see her after a long while and she would show no surprise or disappointment or curiosity about what you had been doing in the meantime. And she talked of her father and how he liked conversation and now he could not even have that. She shared her father's puzzlement and seemed to be asking that the group would be to her like her aunt and make ordinary and matter-of-fact what was strange and threatening to her.

Mrs F, the third carer to speak, had been married for 40 years and for all but the first two years her mother had been living with them. The group heard about a succession of illnesses: 'almost everything was wrong with her'. Her mother had been in and out of hospital and most recently had gone to the psychiatric hospital for assessment. Mother's comment: 'They asked me questions to see if I was mad.' The daughter, upset by the psychiatric ward, took her mother home – against the advice of the GP, she said. Her mother is now living with her and her husband in their maisonette. Mrs F reported that the mother had hallucinated, was talking to the mirror and repeating what was said to her. At night her mother said: 'Get some rest, my dears, I pray to God I won't sing tonight.'

It would be difficult to say specifically what Mrs F was looking for from the group. She was wanting to tell her story. Others intervened with questions and suggestions but they hardly interrupted the narrative. Finding a sympathetic audience to whom to tell the story may be as rare for some carers as going on holiday.

The fourth carer was still coming to this group, although her elderly relative was now in institutional care. She acted in the manner that one might expect of a facilitator in the group, offering reassurance and linking the things that were being said. The worker brought the meeting to an end but this did not stop the participants talking. They were saying how their old people were so active that they wore them out. In turn, the workers now also experienced the difficulty of getting away! Throughout the meeting, a resident from the old peoples' home was pacing up and down outside the door: no one bothered her, and she seemed to bother no one.

A small discussion group at another conference was cautious about the idea of support groups for carers. It was argued that carers need all kinds of support and that a group might not suit everyone. One carer had not wanted to join this discussion group but, nevertheless, was very clear about her needs from her point of view. She wanted a washing machine. She well represented a common feeling among carers of being trapped at home, and not having time for 'going to a group'. Nonetheless she had accepted help from the conference organisers to enable her to attend.

A social worker in the same discussion group was about to set up a relatives' support group. She and her colleagues were facing pressures to turn it into a client group. Was the carer who wanted a washing machine presenting herself like a client, asking for help in a way that suggested that no help would really be acceptable? Her experiences had forced her to rely on her own resources, and she was unwilling to depend on other people again.

A worker with MIND had found that carers have natural group skills. There was always pressure on the social worker, the health visitor or other workers to move on to new problems, but for the carer the problem of continuing care remained, as did the need for support. A social worker explained the limits of her commitment. 'When my client is eventually admitted to Part 3 care, how can I justify keeping the case open to work with the relatives?'

In such conference discussion groups, as in the monthly workshops at the London Voluntary Service Council, people took a consistent ideological stand – that a carers' group should become what its members wanted it to become: an intensive emotional self support group, or a pressure group fighting for better facilities, or a social club, or a mix of all three. The danger was recognised that relatives' support groups could become staff support groups. Professionals working with the elderly can bring with them inappropriate attitudes, seeing relatives as a resource to be trained to do better and to carry on longer, rather than people under stress with needs of their own.

A voluntary organisation worker who has made a particular study of working with carers emphasises the importance of not imposing the time value of work on those for whom time has lost its sense of urgency.

> The rules I have made for myself with clients' help are, to be punctual, to be flexible and not to be rushed. One day I

> unfortunately arrived late and said I could only stay half an hour as I was expecting a telephone call. I was told firmly if I was going to be like everyone else, including the family, rushing in and out, not to bother.[19]

The Association of Carers does not limit itself to any one 'client group'. Judith Oliver has suggested that it is something of a contradiction in terms to develop group support for carers to answer their personal needs and yet categorise them in terms of the illness or disability that they manage.* The key factor is coping with dependency and the loss of self which can accompany the caring role. The Association is looking beyond practical help to giving emotional support to enable carers to draw on the experience that they alone have had; for example, the impact of caring on their sexual lives. A mixed group has much to learn from its diversity of experience and it helps to limit competition between carers.

The Equal Opportunities Commission has not only recognised that the vast majority of carers are women but that caring for many of them is, or seems to be, life-long, involving a succession of relatives, children, parents and in-laws and finally perhaps an ageing husband.[20] Divorce rates, estimated now to affect one in three marriages, can bear as heavily on the elderly as on children, as has been pointed out by Chris Rosseter and Malcolm Wicks of the Study Commission on the Family.

> We do not know for instance whether women are equally willing to care for ageing step-parents or ex in-laws needing support. We are similarly uncertain about the effect of re-marriage on completed family size. If step-families prove larger, this too may affect a re-married person's capacity to care for older relatives.[21]

We would find our way of life terribly exposed if increased demand for care coincided with disruption of supply, causing dramatically increased costs to our systems of health and social welfare.

In the family context a relationship exists (itself a complex mix of affect, social organisation and economic activity) into

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* Association of Carers, Medway House, Balfour Road, Rochester, Kent.

which is introduced the additional factor of the increasing debility of the old person. The fact that the relationship has usually been established long before the onset of infirmity distinguishes familial care in most cases from any subsequent potential sources of help. Also, the GP, who may have known the family at different times of crisis, and neighbours may offer support according to a principle of delayed reciprocity going back many years. Where immediate gratification in the care of mentally frail people is hard to find, it is difficult to overestimate the importance of establishing a commitment before they have become so mentally frail that they are unable effectively to mobilize help.

The onset of mental frailty in elderly people is hardly noticed, as members of the Alzheimer's Disease Society are aware.* A growing awareness of odd behaviour takes time to be translated into a definite but unproductive diagnosis: 'Your mother has senile dementia, there is nothing we can do.'

If the person is living with the family or close by, the GP typically expects that the family will cope. If the person is living alone, the GP is unlikely to be asked to make a diagnosis until there has been a breakdown, unacceptable to neighbours or professional workers, of the person's ability to relate to the social environment. In this case the GP might also look for ways to transfer his elderly patient out of his own 'primary care'.

The family has an implicit contract with the old person and it could be said that there comes a time when its members have to look at the small print. The progression of mental debility in old age conflicts with the normal expectations of family life. All relationships are turned on their heads when an elderly woman treats her daughter as her mother. Family care is often 24-hours a day, seven days a week – without a shift system. We talk of family, but the responsibility may be carried mainly or exclusively by one member – in professional terms, the 'key worker'. It is a relationship of mother to daughter or wife to husband. Of course, other members of the family may be involved, but increasingly the needs of one

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* Alzheimer's Disease Society, Bank Buildings, Fulham Broadway, London SW6.

member can become at variance with those of the family as a whole.

The family care of an elderly dependent relative may take on some of the characteristics of a closed system, effective in its own terms in containing a social problem about which it may have feelings of shame and guilt. If its experience is one of isolation and lack of support, the family may seem to be working well within itself but increasingly unable to relate effectively with outside agencies. Social relationships are undermined and offers of help, official and unofficial, are often rebuffed. If the process continues unabated, this system of care may finally cease to function. Institutional care becomes the only alternative. The crisis reinforces the family's guilt and resentment. The community support services, whose task it is to moderate this process, will be subject to the same conflictual pressures. This is hardly surprising, for they may also be at a loss to know what to do with the elderly.

Health and social services and the sharing of responsibility

Community care can be either care in the community or care by the community. In general usage it is often implied that the first option leads to a second. Faced with evidence that this does not happen, we still assume that, somehow, the community ought to care. This assumption – by talking of community we disguise the burden of expectation that we are putting on the family – is at the basis of a lot of thinking by those with responsibilities towards the community. For example, hospital based services, both health and social services, define their task as getting people better to go back into the community; sometimes they implement this policy by discharging people at weekends, when mainly the informal carers are on duty. Both health services and social services ration their limited resources by giving priority to elderly people who are not getting care in the community. In this sense, the key worker role in the statutory services is the equivalent of – if not the substitute for – the unmarried daughter in the family model of care.

The overlap of health and social services in giving community support to dependent elderly people is such that collaboration may seem to be not so much a problem as an inevitable working practice. An established way of managing a commonality of interest is the case conference, a working meeting with the task of arriving at particular outcomes around the needs of patients and clients. Inter-group activity of this sort can be a way of regulating the relationships between different services.

I attended several meetings of a monthly conference, set up to be collaborative, held in a health centre and chaired by the team leader of social services.

> Meeting together in this way reduces anxiety and all those phone-calls checking up on what each other is doing.

Apart from the social worker, there were geriatric visitors, health visitors, a senior nursing officer with responsibility for geriatric services, a community occupational therapist and physiotherapist and a home help organizer, and a representative of the housing department. The conference allowed them to discuss clients of common concern. Anyone could bring a case. Usually notice was given so that others could look out the appropriate file.

This structured format with a level of informality allowed for negotiations that were largely free of the defensiveness of inter-agency demarcation disputes. Here are some examples.

> Mr B – This case was introduced by the geriatric health visitor. Mr B had moderate dementia but there had been a sudden deterioration and he was frail and unkempt. A referral was made to the GP in the hope that he would be admitted to hospital, but this had not happened. Family care had dropped away following his deterioration. The district nurse was visiting daily and he had a home help and meals on wheels. The patient was opposed to making an application for Part 3 but he could not cope where he was.
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> The social worker reported that he was a frightened old man, who should not have been discharged from hospital on a previous occasion. The discussion that followed in the case conference removed any ambiguity that Mr B was a 'medical problem' and there was no appropriate further intervention to be made from social services.

Miss A also suffering from dementia, was supported by a neighbour. The conference was concerned about her behaviour – peering through letter-boxes, thinking that her mother was still alive – and gave encouragement to the geriatric care visitor who was going to visit the neighbour.

Mrs M had a daughter who lived 50 miles out of London. The daughter was asking that her mother go into an old people's home but she herself had refused. It was reported to the meeting that she was now agreeing to look at one or two local authority homes.

Mrs S was unwilling to accept Part 3 but could barely cope at home. The geriatric visitor was asking what could be done? The social worker replied that they might consider an emergency admission, which would result in her staying in a local authority home. A neighbour was reported to be 'cheesed off'.

Such a sequence of cases was quite usual. At times it seemed that the group's task was about managing the transition from care by the community to care in the community; that the main protagonists were the geriatric visitor and the social worker, who were mostly in agreement about difficult cases – their difficulty arising from the determination of old people to stay in their own homes while those around them thought them to be living beyond an acceptable level of risk. An indicator of risk would be the disturbance caused to others.

This was certainly a group that was prepared to hear the appeals of family members or neighbours for relief from continuing care, lest the case reviews did not lead to specific action. They were, as the social worker suggested, ways of managing the anxiety of people working with the elderly. One purpose of conferences was to give the participants the confidence not to intervene, at least for the time being. Discussions around the needs of the elderly people took into consideration their rights to self-determination. The multi-disciplinary dialogue allowed participants to tolerate this independence of their patients and clients and shifted emphasis from resource allocation to the ethics of care.

> Mr H was a widower who lived on his own. He rejected the services offered to him, meals on wheels and home helps. He was bronchitic, unreliable with medication and lonely. In this case there was no family support. 'He brings the nurse out in all of us.'
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> The social worker suggested that he might go to a social services day centre. The health workers thought that he was too unreliable for that. If he would accept the meals on wheels, they might be able to check on medication. In the meantime, the social worker thought there would be a delay before it would be possible to allocate a social worker to this client. The geriatric visitor accepted this, saying that it was not urgent.

Alison Norman has described some of the risks to civil liberty in old age.

> If avoidance of risk is indeed a prime objective, moving people out of their homes may not be the best way of achieving it ... The more they appear to be at risk where they are, the worse will be their prognosis if they are moved. Yet this is a factor which is seldom taken into consideration when considering transfer to residential care and still less is it taken into consideration when deciding on hospital admission.[22]

Month by month the meetings 'monitor the progress of those who are most at risk'.

> The geriatric visitor had said that he would visit the neighbour who looked after Mrs A at weekends. One problem had to do with the management of money, as Mrs A would hide her rent; it was uncertain who was holding her pension book. Social services were able to give the information that Mrs A had a son, who had come to the office to explain that he did not have the pension book. In the meeting it was agreed that the neighbour should be encouraged and supported as much as possible – and should have the pension book. Mrs A was causing a lot of disruption to others by her behaviour and wandering. The housing officer reported that there had been complaints from other tenants in the estate.

'It would be better if she had been left to wander out at night, at least Dr—— (geriatrician) would make a decision then.'

This exasperated comment made by the nursing officer was not cruel to the patient. It was a reference to the apparent unwillingness of the GP to make a referral to the geriatrician.

Mrs S used to go to her luncheon club but had not been seen there in recent weeks. Social services had received a call from Age Concern that a friend had attempted to visit, had looked in and seen no furniture, but could hear a dog barking. In the discussion it was learned from housing that Mrs S's neice held the tenancy of the flat and the housing department would investigate the matter.

These debates suggested that the multi-disciplinary balance partly ensured a mix of competence in a strictly professional sense, but also encouraged discussion of the ethical issues involved.

The conference also had to deal with a further complexity – that those who most need institutional care can be those least willing to accept it; furthermore, they may not even accept domiciliary care to maintain them where they are. For this group, admission to hospital on medical grounds was still a possible way out of an impossible social situation. This was the cause of the anger directed at the GP who 'saw no point' in making a referral to the hospital consultant.

The conference gave support to a social worker, who had to face the limits of his authority. His client had discharged herself from hospital and had nowhere to go; her previous home was no longer available. She had been shown Part 3 accommodation but had consistently declined it. The worker had to see her walk off down the street after rejecting all offers of help. Ultimately, the client was acting on her own authority, although no one had any doubts that she lacked the capacity to look after herself.

In this case no service was to blame for not doing something about it and the conference was able to relieve a participant of some of the pressures of omnipotent phantasy.

Bridging the gap to informal care

The health and social services are often in the dark about family care. For this reason staff in the psycho-geriatric department of a hospital have suggested setting up a mobile support unit for caring families. The staff came to realise that most families felt 'at sea', particularly during the early stages of dementia, and that caring families were reluctant to resume responsibility for an elderly relative after a period of in-patient care. Discussion with caring families disclosed some common themes.

1. Due to the insidious nature of the illess, a considerable amount of time elapsed before the problem was recognised.
2. All the relatives were unsure and poorly informed of the nature of the illness and its history and welcomed a clear exposition.
3. Common problems relating to the affected relatives were: i) incontinence; ii) wandering; iii) accidents; iv) distressed behaviour; v) mental illness; vi) hygiene.

Relatives suffered from isolation, particularly those who were having to do caring on their own; there was a severe curtailment of their life style, stress in families and friction with neighbours.

> Families spent a considerable amount of time unsure of the alternatives. Once on course, they felt frustrated by bureaucracy, scanty information and poor co-ordination. There was a feeling that the range of resources available were sufficient: the problem arose in discovering the resources and gaining access.
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> Most of the families had coped remarkably well, they had learned a good deal and felt they could offer advice to similarly affected families, e.g. who to contact, how to cope with specific problems, etc. They all believed that, given sufficient information, assistance and 'sense of support', they could have coped for longer with an improved quality of life for both themselves and the affected relative. As it was, a major crisis had arisen and they would be reluctant to resume full responsibility again.[23]

Two proposals came from this evidence – that a family support group should be established in the hospital and a mobile unit set up to encourage community support, the unit being attached to day centres and health centres and other places where carers – actual and potential – might be reached. The mobile unit would offer information, advice and practical assistance, attempting to improve the quality of life of informal carers and those for whom they care. Potential crises could be delayed and avoided by breaking down the exclusivity of the formal sector as experienced by informal carers.

> The social worker, occupational therapist and GP are all seen to be visiting their patient or client and to regard as an intrusion (and a fairly selfish one at that) complaints of other members of the family. Even when the carer himself is ill, the needs of the statutorily acknowledged 'sick' person come first, though the carer may be the one who is acutely ill.[24]

Two workers based in a geriatric hospital wished to introduce the concept of relatives' support groups for carers with elderly relatives in hospital but found they had to take account of the 'negotiated order' of institutional systems.[25] Other staff had different status relationships and took different theoretical attitudes towards treatment and care. Differences occurred not only between the professions but within the professional groups about the division of labour inside the hospital. The two workers, a social worker and a volunteer organiser, had difficulty in keeping their initiatives to themselves in a small hospital with only 120 patients. The concept of small group work with informal carers was transformed into a public function representing all the different disciplines. If hospitals may be thought to have some of the characteristics of community systems of care (except that they have been brought indoors on one site), evidence is likely to be found also of a 'negotiated order' in the provision of day care and other resources for elderly people living at home; and if the different professions do not feel involved, they may be slow to refer patients and clients to informal and small-scale day care resources.

The social worker and the volunteer organiser came to the project's monthly workshop for people developing services supportive of informal carers, held at the London Voluntary

Service Council. There they had the opportunity to experience some of the conflicts that the participants had among themselves about ways of supporting informal carers. My notes after an early meeting referred to this apparent institutional/community split.

> One consequence of having a mix of people was that the different aspects of the work get associated with other differences. Those who work in a hospital or institutional context have certain clinical and therapeutic priorities, often to be put beside obligations for continuing care. Those working with the problem of elderly people in their own homes have other priorities and the elderly are not in the same sense so dependent on them deciding how they may live. In the circumstances, the differences may serve to express different aspects of working with informal carers, meeting their needs for education and encouragement as well as realising their own potential as a resource for elderly mentally infirm people. In the workshop it seemed at times as if the need for structure and a sense of direction belonged only to those representing hospital systems of care while the 'community' offered an undifferentiated model in which nobody had any particular skills.

A way to resolve this problem has been explored by a local MIND group with active support from a consultant in the psychiatry of old age. Given that self help organisation, supported by social work and other professional inputs, is meant to bridge the gap between the needs of elderly people and their carers and the resources of the different agencies, the organisation was expected to provide the following:

- by counselling, advising and, in particular, by the use of group therapy, to assist those caring for elderly relatives:
- by sharing the load of looking after confused elderly relatives, to enable members of the group to regain a degree of independence and have some time away from home;
- by bringing together people shouldering the same burden, to give each member of the group the opportunity to deal with the conflict of loyalties they were experiencing;

- by providing the opportunity for members to learn from each other, to improve the help given to the mentally infirm;
- to help relatives to reintegrate into society after the death of a patient.

The counselling and support was aimed at different socio-economic groups to find out whether or not there were different needs, and to provide an opportunity to exert political and social pressures to obtain money for an area that is under-resourced. As a result groups were established in day centres and in an old peoples' home.

> Each group is different in its make-up of clients and the way in which it develops, though some common themes and practices have emerged ... Worries about the onset of disease in the relatives and the causes are much discussed, as are desires for a 'miracle cure'. Fears about the level of support and the effect on the family of the carers are aired, as are the strains of depression and isolation and the carers concern on how to carry on. One very heartening aspect of the group is to see the support given by a long-standing member to a newcomer, though it has become clear that it is not possible for the groups to be totally self-supporting, mainly due to the age of the carers and the burden that they are carrying.

Voluntary organisations and day care

The volunteers working with elderly people in a day centre show a marked antipathy to social workers on quite simple grounds: 'They don't understand about dementia'. The criticism does not have to be taken at face value but we should ask why it is made. It comes from the volunteer worker identifying with the 'informal' end of the care continuum. A way of working that appears to be brusque and to the point is suspect; for how can it be relevant to a condition that is far from brusque and rarely ever to the point? Understanding the problem is difficult, but anyone who thinks that arranging for a supply of incontinence pads and a half-day at a centre is the answer has a lot to learn.

Day care for mentally infirm elderly people is at the interface of formal and informal systems of care. The medically orientated view is going to be different from the social work view. Day hospitals keep people out of hospital by extending the disease model practices of hospital-based care to outpatients; in contrast, day centres keep people in the community by introducing the kinds of structured activities that they might otherwise get only in institutional care. To be effective, of course, neither day hospitals nor day centres should keep to such exclusive interpretations of their tasks. They are outposts from the entrenched divisions of health and social services and as such have attracted a lot of attention from those looking for ways of developing an integrative approach to the care of elderly people.

Day centres for the elderly mentally infirm organised by the voluntary sector may be seen as a test case, offering evidence of services built around the needs of people who do not give any of the usual satisfactions in health welfare provision. Voluntary organisations not only have an independent stance in relation to health and social services, but have access to informal carers, the families and neighbours involved, and also to volunteers able to offer some relief to these carers.

The attitudes and motivation of some volunteers may be thought to be particularly suitable for this work; alternatively, it can be argued that it is too stressful for volunteers, or even that they might exploit and abuse people whose main characteristic is their dependency. Those planning a new day centre argued in favour of volunteers.

> It is hoped that the attitude of the volunteers will encourage individual activity and group participation while providing a stable reassuring atmosphere.[26]

This statement suggests that volunteers are free of some of the prejudices shown by professionals; that a volunteer can relate to people naturally. It is an image designed to counter the professionals' belief that volunteers can be moody and unreliable.

The centre in question was for forgetful and confused elderly people. It had an initial glut of referrals – two thirds from social workers and social welfare offices – which included a wide range of clients who were a problem for the people looking after them. The drought that followed the glut indicated that the social workers had run out of options for these clients and were using the centre as a place to 'offload' them rather than as a potential source of help for elderly people in the early stages of mental confusion.

The centre is called a club; the elderly who attend it are the members and the rest, mostly retired people, are the volunteers. A worker from Age Concern had the difficult job of acting as facilitator/enabler in an atmosphere that was stimulating within the narrow limits of the club members.

For this kind of provision to be effective, the professional workers have to slow down to a pace that others can follow. The success of such a club presupposes drivers and escorts being available, who have the patience to transport people who do not know what time of day it is. Members of families may be best qualified for this work since local authority drivers need training and the support of flexible rostas.

Many of the techniques of reality orientation now attracting attention can help volunteers to relate to people who cannot give the usual social satisfactions. Volunteers can be supported by psychologists and other professionals in developing structured activities to stimulate people with poor short-term memory.

The impression was of people in slow motion making activity purposeful for themselves. On one day there were four members present, on others there might be seven or eight. They were physically frail and some had difficulty walking, sitting and eating. Each would have to be accompanied to the toilet. One would go out into the garden if she could be given sufficient reason for doing so. The problem for the Age Concern worker was that the volunteers interacted more with each other than with the members.

The preparation of the midday meal took up most of the activity of the morning. Two members were allocated washing up duties and the worker sat with another member and made cup cakes. A woman member was given some knitting to do and a man was taken for a walk, albeit reluctantly. Two other members made woolly balls. Inevitably the conversation separated out, the volunteers increasingly talking among themselves. They sustained a mode of gentle animation that did not contrast harshly with that of the members, who tended to respond politely but briefly to enquiries put to them, but did not initiate discussion. What the volunteers had to offer was their natural way of relating to the members so they did not noticeably lead them into conversation. The mid-day meal – chicken and rice – was for everybody equally. The volunteers came to the club for their dinner as did the members.*

It could be said that this day centre is unambitious in its aims, but this criticism would come from applying the wrong criteria. In an anthropological study of a day centre for the elderly, Haim Hazan suggests that old people may eliminate much of the past and future in their lives and exist satisfactorily within a repetitive, and therefore unchanging, present. He argues that this arrest of time is no bad thing but useful to the old people in renewing their social 'being'.

> The Centre presents a sharp contrast to the values and the ways of the outside world and in content and structure it represents an alternative viable social reality. The repetitive nature of events coupled with the more verbally explicit revision of the past and the obliteration of the future create a new constitution of time in which change is arrested and progesess and planning are eliminated; yet people find themselves doing meaningful, purposeful things within a well-defined structure social arena.[27]

In the club described, the volunteers would have thought that a more active intervention would be to misunderstand the members' needs.

> You can't expect them to join in. We play bingo but they don't look at the numbers.

Those planning this day centre had wished for more structured activities, reminiscence work and reality orientation, and this brought the workers into conflict with the volunteers,

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* For further information about Age Concern day centres, contact Age Concern Centre London, 54 Knachbull Road, London, SE4.

who saw themselves as working without support in their efforts to keep the club going. The volunteers needed to see order triumph over chaos, and in this sense the club belonged to them. Their anxieties – whether dinner was going to be served on time for example – could be seen as standing in for the more global uncertainties of the members, some of whom would not remember the club from one week to the next.

This kind of resource, though useful, might be thought to be below the dignity of the health and social services, as it was neither preventative nor crisis orientated. However, another day centre for mentally infirm elderly people organised jointly by Age Concern and MIND, took a more active stand in relation to the statutory services. The workers in the voluntary organisations thought that they would be considered cantankerous by health and social workers, a self-assessment that was made with some pride, as if it would have been wrong to be otherwise. Although referrals came from the social services, this in itself did not ensure continuing co-operation. The workers might contact the social services department about one of their people and find that the social worker had closed the case.

Both of these day centres were set up by workers in voluntary organisations with back-up from the statutory services, in particular the social services. Another example was a more equal partnership between social services and the local Age Concern. The area manager of social services and the Age Concern organiser had discussed the need for locally based day care centres for elderly mentally frail people, but agreed that neither had the resources to put their ideas into practice. Eighteen months later new workers had been appointed on both sides and it was possible to agree a pilot study with funding from social services and private trusts. The pilot scheme was to be coordinated by the social services and Age Concern.

What are the advantages of this sort of partnership? It was, in the first instance, a breakthrough in providing services for a very independent group in society. Arguments supporting the scheme including statistics from a geriatrician, suggesting that there were up to 4,000 old people in this particular London borough suffering some degree of mental frailty.

Nevertheless, resources could not be diverted; they had to be created to meet this newly understood need. Age Concern claimed particular expertise in the recruitment and support of volunteers.

> It should be kept in mind that more often than not it is the pattern of daily living that most of our clients have lost or are unable to cope with and re-establishing this pattern will be the major role of the centre. Trained or untrained, the volunteers will have a lot to contribute to the clients of the scheme that way.

The use of volunteers contributed to the low cost of the scheme. The dream was to have many similar groups in order to get away from expensive centralised resources, which were not going to be available anyway.

The use of small informal groups underlies the thinking about such centres.

> 1 To reduce as far as possible the disorientating effects of moving elderly confused people from familiar environments.
> 2 To minimise the difficulties and cost of transporting the clients to the centres. It was also thought that the relatives/carers would be more able to take on the responsibility of transporting clients to the centre if difficulties developed.
> 3 It was hoped that locally based centres would attract volunteers with a high degree of commitment to the centre, being, as it were, 'right on the doorstep'[28]

Thinking about what is really needed is made difficult because informal carers are not usually in a position to make their views known. One of the advantages of relatives' support groups is that informal carers, often isolated, unsupported and 'invisible', get together and may even be able to make their needs known to planners of day care services.

In one London borough, an Age Concern worker, who knew carers through the group work that she had organised, was able to set up a meeting where carers could put their case to the chair of the social services committee and the chair of the district health authority. The carers emphasised the need for day care centres and transport. The chair of social services said that they were reviewing their concepts of what was meant by care of the elderly. A social worker explained that confused elderly were on the margin of established services. The principal social worker said that the old peoples' homes in the area offered day care, a possibility that was news to the carers at the meeting.

Transport problems were the cause of the under-use of the geriatric day hospital at the district general hospital. A carer reported that the hospital geriatrician had said that there would have to be a way of separating confused elderly people from other patients before the elderly mentally infirm could use the day hospital. The representatives of the health and social services both emphasised that it was a question of finance and priorities. Health services were being cut back and to develop services for the elderly mentally confused would be to compete with other parts of the health services – just as elderly mentally infirm people were competing with other groups for social services' resources. Both said that elderly mentally infirm people who lived alone tended to get priority for whatever services existed.

A woman who arrived late to the meeting identified herself as a carer. Her mother was presently in hospital and was about to be discharged home. She had been talking to a social worker and thought that day care for five days a week had been promised for her mother, enabling her to continue in full-time employment. She had been surprised by the discussion about lack of resources; in turn the other carers stared at her in disbelief. She was advised to find out whether the day care existed that she thought had been promised!

Planning effective day care is inhibited by cost, even though it may be less than care in an institution. Two workers with experience of running a day centre submitted a proposal to a planning group – multi-disciplinary, convened by a consultant psychiatrist – looking at ways of developing services for mental illness in old age. They outlined the aims of day care:

1 To provide a safe and caring atmosphere and stimulating activities for elderly mentally infirm people with

a view to improving their mental alertness and functioning.
2. To give caring relatives relief and help them to continue with the burden of looking after an elderly mentally infirm person.
3. To provide initial and continual assessment of individual elderly people.

The aims may seem to be uncontroversial, but ways of meeting them through day care can appear to be both logical and excessive. Nonetheless the degree of provision which follows is excessive only if it fits uneasily with definitions of care *in* the community and *by* the community.

It was argued that care should be provided seven days a week from 8am. to 6pm. The housing department should be asked to provide ground floor flats in which groups of not more than 12 people could meet. To make these groups effective, each would need its own transport and tail-lift coach with a driver and two escorts. One escort would call for and assist the pensioner, the other would stay with those already on the coach. Members of the group would be referred from social services, health services, voluntary organisations and carers. Joint assessments would be made with the referring person. Staffing would be managed by an organiser with an assistant and five other workers. Each group would have the services of a GP on a sessional basis, also a physiotherapist. Members of the local community would be encouraged to become involved in its activities.

The ground floor flats would be converted to provide a dining room, a kitchen, facilities for washing clothes, a bathroom, an activities room and three toilets. Adaptions would provide sufficient room for people in wheelchairs, even though the number attending at any time would have to be limited.

Some members of the group would come every day, others one or two days a week. This would depend both on their own needs and those of their carers. Reality orientation would underpin all the activities of the day. For example, cooking would be integral to the activities. It would be the responsibility of one worker to prepare the meals with small groups of pensioners. There would be breakfast for those who came early, lunch for everyone, and tea for those who wanted it. Informal carers would be welcomed and invited to tea. Pensioners would be involved in preparing tea and coffee and also doing the washing-up. Other activities might include knitting, sewing, an assortment of card games, some arts and crafts, and music – again with pensioner participation, for example, playing the piano. There would be exercises and outings, as well as everyday interaction with the more structured reminiscence work.

This model of care makes specialist workers peripheral and puts management in the hands of the day care organisers. It involves ordinary people; gives relief to informal carers without excluding them; is an example of an ideal of service that is seen as outside the mainstream provision for highly dependent people. Day care of this kind is considered to be expensive and impractical – less of a priority than the provision of assessment beds in a district general hospital, the sine qua non of the appointment of a psycho-geriatrician. What may seem to be the appropriate scale of activity for the task at a local level does not ensure that the provision is sufficiently vigorous to survive the planning process.

The integration of professional and informal care

The relationship of the skilled worker to the unskilled carer is theoretically straightforward. The dependence of the carer is satisfied by the expertise of the worker. The commitment of the worker is rewarded by the ability of the carer to carry on.

These statements imply that voluntary activity is, or should be, subsidiary to paid work and should not encroach on traditional areas of work of the statutory health and social services. Resisting cuts in services imposed by economic policies has reinforced the determination of the voluntary sector not to fill gaps left by the loss of appropriate statutory services.

Distinctions between paid and unpaid work can be surprisingly confusing. It is not always possible, or even desirable, to make a rigid separation between working relationships and social interaction. The overlap of meaning of what is a work responsibility and what is a social responsibility has implications for people wanting to share their common concern around the care of an elderly person. They would find it easier to manage the differences between them if they could be clear about the true nature of these differences.

People working with volunteers have had a long experience of trying to sort out what is appropriate for voluntary activity and what is the proper responsibility paid workers. The Volunteer Centre consulted NALGO when producing guidelines,[29] and The London Voluntary Work Development Centre – now Advance – has also tried to establish principles which respect paid work while defining priority areas for voluntary action.*

Workers in a neighbourhood care project identified three difficulties in their relationship with volunteers.

1 The volunteers claim to own the show and the workers therefore feel unskilled. Whatever they do, their abilities and experience have to be denied so as not to obscure the image of the volunteer doing his thing.
2 The workers feel both guilty and resentful about their low pay, feelings that cannot be worked out with volunteers who are paid nothing; also, it is not possible to order volunteers about like workers because one always had to be grateful to them.
3 The workers are held accountable for the mistakes of the volunteers.

Volunteers are at the formal end of informal care, or, if they are organised differently, at the informal end of formal care. Attitudes towards volunteers and the management of what they are doing, are a reflection of the boundary conditions between the formal sector – direct service provision – and 'informal care'.

As we have seen, the informal carer is not peripheral to the statutory services in providing essential care to the frail old person at home. It is the other way round. Should not the nature of the work help to determine who is the best person to do it?

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* Advance, 14 Bloomsbury Square, London, WC1.

Roger Hadley and Stephen Hatch have made a distinction between bureaucratic and participatory systems of social service organisation.[30] A volunteer coordinator working in social services may have to integrate the two kinds of systems.

> In terms of development, the volunteer coordinator has a role in stimulating the growth of volunteer schemes to tackel unmet need . . . I continued to collect information for area team workers on clients' needs for voluntary or community support, particularly those remaining as yet unmet. This is an essential area for team co-operation.

This justification of his work was by a volunteer coordinator based in a home care team, 'home care' itself being a recent priority, an attempt by social services to integrate their work better with the day-to-day realities of their clients' lives. The volunteer's role may be seen as bridging professional and informal care, introducing replicability and accountability to a natural response to need.

For example, insistent demands are heard for expert advice to be made available to old people and their carers. It is something that paid and unpaid people in the caring network seem to be agreed upon. So the problem is not so much how voluntary action encroaches on the safe ground of statutory services but how health and social services can do more to relieve the pressure on the voluntary sector – and beyond that on informal carers who are carrying the main brunt of the care of mentally infirm elderly people and gaining representation and a voice in affairs. A statement by one carer speaks for many:

> The doctor told me that my mother had senile dementia and said to go home and look after her. It wasn't until I met – [worker in voluntary organisation] that I found out just what was available and it was too late. Till my mother went up to the centre two days a week, I couldn't get out of the house.

The geriatrician Klaus Bergmann, in an article on 'How to keep the family supportive', argues that support for families has to come before stress turns them into rejecting families. Support offered too late will be rejected without gratitude, a reaction that professionals usually recognise as characteristic of rejecting families.[31]

The brief intervention of the professional worker has to be good to justify its brevity. This is especially true for workers around people whose pace of life is very slow. It is not surprising that they assume a correlation between the briefness of the intervention and their expertise, because the doctor is trained to diagnose in seconds what the nurse has observed for hours and the carer has experienced for days, weeks or months. Carers say that their dependency on the experts may be disappointed. Their continuous experience of a confused old person leads them to find their own answers; whereas those making brief interventions are exhortary, but powerless to alleviate the situation.

To ease the situation may mean going for greater expertise than is found in the management of specialist services. It could come from extending the expertise of informal care into paid work. This is illustrated in the application of care attendance schemes to the needs of the elderly mentally infirm.

Work with carers often starts as an extra commitment over and above anything in a job description. The problem then becomes how it is to be integrated into the main stream of work. Such initiatives often depend on the enthusiasm of individuals prepared to work unpaid overtime, but if you are the manager of an under-staffed day centre, it may not be easy to take time off in lieu. Also it is paradoxical to expect workers to support carers if they themselves are feeling equally overworked and exploited.

Efforts are being made to get funding for paid work, which relieves and supports informal carers. The increasing use of paid workers in home care projects, which support carers, is a sign of a new consciousness about carers as the main source of continuing care in the community. However, we should ask what is the nature of this paid work, often the product of collaboration between agents of the existing services.

In 1983, a new scheme was being planned by a committee chaired by the area manager of the social services. The secretary was from the local Age Concern. If the application for joint funding was successful, the new workers were to carry out for a few hours the sort of duties that an informal carer might be expected to do most of the time. The relief provided would be along the lines of the Crossroads Care Attendant Scheme, which was originally set up for the younger disabled people. The discussions brought out important similarities and differences between the workers and the carers. A difference to the workers' advantage was the recognition that they would have to be protected from some of the stresses of the job, with a short training course, limited hours, the prior assessment of clients, and so on. A further difference from other 'official' carers, the home help service, say, would be that the workers would have to be taught how to lift people, because they would be expected to do it, whether they were trained or not.

It might have been thought that the job description for the paid workers would become a draft bill of rights for all carers. However, it turned out to be an ambiguous document. There were to be 'paid volunteers', straddling the divide between informal carers and paid workers, paid less than home helps for the time – up to eight hours a week – when they relieved members of families.

There are practical and rational explanation for this kind of arrangement. The most succinct was that it is the only way the scheme was likely to get funding. The paid workers accountable to the local authority would be the coordinator and administrative assistant, both new posts. Perhaps the other workers had to be 'paid volunteers' because they were, after all, only doing the work of informal carers, – and these carers are not 'workers'. Talk of paid volunteers makes the old distinctions between 'work' and 'not-work' creak at the seams.

Some professional workers with the elderly are, or have been, carers in their own families. Their experience not only provides the necessary motivation but the insight and understanding that otherwise would be missing in a professional training. For example:

> Mrs E is a hospital social worker in her mid-fifties. She was recommended within the social service department as someone worth talking to, as she worked with and had an interest in the problems of mentally confused elderly

people. She had chosen to work in a day centre for elderly people because of her own experience of caring. She was able to be critical both of families, who expected the statutory services to take over care of their dependent relatives, and also of colleagues not giving priority to the needs of the elderly.

One professional, writing about experience with an elderly father-in-law, has stated: 'It is much, much easier to instruct people on how to manage their elderly relative than to cope with your own.' His social work and nursing experience in mental health did not stop him describing himself as ill-informed and the local and central government guidelines on care as bland nonsense.[32]

Another worker ceased to be a health visitor to look after her 78-year-old mother-in-law. In that way, she learned about help from caring professions.

> I asked the OT for advice on how to keep mother occupied during the day. I was also having difficulty in teaching mother how to use our gas cooker and the electric kettle and wondered if the OT would succeed. The short reply to my questions was that they didn't do such things in the community. There were many occasions when I wished it was possible to discuss this sort of thing with a professional and have support and encouragement. In desperation, I rang the social services one day and was told that a volunteer would come and show her how to make a basket.[33]

She also learned about day care.

> I rang the social services department to ask about a day centre. A young social worker later came to visit us. I'm afraid mother had no respect for him on account of his very informal clothes and long hair. He arranged for mother to go to a day centre 5 minutes walk away. The day centre was never really successful. Mother and I went together the first time and had coffee there and met the staff. It took two or three weeks to persuade her to go again. She would agree to go, I would ring and book her lunch. The next day she would be ill. It was very difficult to reason with her and explain why we wanted her to go. She finally understood that to go was a favour to me.[33]

What is this distinction between the responsibilities of the statutory services and those of the family and informal carers?

A worker in a voluntary organisation responding to the need of an old person she knew, complained bitterly about the inability of the social services to put in a home help for him at the time he was to be discharged from hospital. The worker reacted by cleaning the flat herself. This was no easy task and left her very tired as well as angry. She acted in fact as a relative or neighbour might have done. A social worker she met in a support group argued that she wanted to scrub out the old man's kitchen in order to do something, but was not sure that this was the appropriate reaction. The social worker was unable to act in this way and had to work in and live with a health and welfare system which provided most of the supportive services that were available; and she knew that all systems of care were inadequate. Later, the social worker reflected that she did not feel irritated or impatient with carers and volunteers, but with workers in the voluntary organisations. Carers and volunteers are still protected by the status of 'client', while the worker has to compete as a 'colleague'.

This distinction of client and colleague is not cut and dried. The volunteer worker is thought to act like a client while, with the new emphasis on informal carers, workers are having to learn to treat clients as colleagues. (Whether this is good news for the clients is doubtful. It depends how people are used to relating to colleagues.)

Whether making referrals to colleagues or advising clients, workers in health and social services feel constrained by issues of confidentiality. This is both a problem and not a problem. It is a problem because there are difficulties in managing the role, determining what information should be withheld. It is not a problem in the sense that the confidentiality issue can be used as a defensive mechanism to avoid communicating with others. In protecting the interests of clients and patients, workers are protecting their own interests.

There are limits to the extent that workers may be able to see informal carers as colleagues. The status of neighbours, for example, is such that they are often excluded from any information sharing. If they ask for information and do not get it, if they do not know even whether their request for help has been heard, neighbours may do the rounds of different agencies. This confirms the agency perception of neighbours as interfering and somewhat suspect, with little or no authority to speak for the needs of the client. A social worker complained of the effect of neighbours' intervention of this kind – causing a reduplication of services. Because they did not know what was being done, the neighbours in effect mobilised all the agencies and, in certain instances, wrote to their MP and the Queen as well.

The basis for suspicion of neighbours may be anxiety about their motivation. The altruism of the neighbour is an unknown quantity, and can be contrasted with the status of the paid carer, whose payment is seen as a form of protection ensuring that the activity of the carer is on behalf of the client.

The relatives' support scheme is a way of structuring the informal support role of neighbours by the use of paid carers. In its first year, one scheme has been giving help to six families, though it is hoped to develop the service to a maximum number of 30 families. The scheme has a part-time (20 hours a week) administrator who matches helpers to families. The helpers work between four and twelve hours a week. Although there are referrals from statutory agencies, it is for the relatives themselves to ask for the service. Most often the request is for granny-sitting but there can be some nursing care – including feeding, toileting, lifting from a bed to a chair, turning in bed, or changing clothing and bed linen. Most of the helpers have nursing or first aid training. They visit a day centre to learn more about the care of elderly people with dementia, in particular when they may become violent – an aspect of care that worries the helpers.

Clients pay £1 per hour for the service. The administrator has the power to waive the fee but has not needed to do so. Most of the elderly dependents are receiving attendance allowance and the relatives prefer a business-like arrangement, which avoids their having to show gratitude by making tea for the helpers. Payment makes the help less intrusive.

Another model for the translation of unpaid to paid care is a 'care workers' project. One functions in an inner city area of high social mobility, where many old people have been left behind, isolated and perhaps frightened by changed in the community in which they live. The care workers, a team of three, cover a small geographical area. The explicit aim of the project is to allow elderly people to retain extensive control over the way they lead their lives. It is not narrowly confined to a specific target group – mentally frail elderly people, for example – but it offers a way of working with highly dependent people. How does this relate to the work of the statutory health and social services? The complexity of the work is equivalent to much that is done by the statutory agencies. The careworkers are involved with dietary advice, personal hygiene, the making and maintaining of personal relationships by people who have most to fear, and also most to lose, from external contracts, counselling and helping people to adjust to frailty and dependence, including the acceptance of change. The relationships of the care workers an clients are both close and professional.

This work is an extension of the informal supportive role that we associate with neighbours. The careworkers experience a striking level of discomfort about their role as paid workers.

> We shouldn't be paid for what we're doing. What we're doing is ordinary caring that other people do for nothing.

They are betwixt and between the informal carers and the statutory agencies. Identifying themselves as surrogate neighbours, they are subject to envious attack from the statutory services and have to justify their distinctiveness from health and social services, including the home help service, by arguing that there is a useful overlap which gives freedom of choice to their clients. Relatives and friends are less frightened by the dependency of frail elderly people if their anxiety is reduced by sharing their worries with care workers, and they can accept more readily eccentric and sometimes difficult behaviour.

At the same time, clients at times find the help of formal agencies to be unacceptable. If elderly people who are frail and dependent are able to project their natural feelings of persecution and threat onto one helping agency, they may then also be able to accept help from another quarter. Working in the community in this way helps with communication – for example, when the worker found out from a discussion in a newsagents' that a client had been discharged from hospital.

The supportive 'neighbour' role of the care worker means that – much like a family member or a neighbour – the worker may feel in conflict with the statutory services. This conflict is about the nature of the commitment. Ms E was a client who saw herself as housebound and had not been out of her home for 18 months. The care workers visited her every weekday and once at weekends. She 'suffered from her legs' and also from paranoid delusions. She was a recluse and kept the electric light turned off and the gas turned down, concerned that she was paying the bills for other tenants in the house. The care workers wanted to work more closely with the district nurses but found them uncooperative. The nurses never returned telephone calls. The nurses who visited Ms E had what the workers scornfully described as a 'production line' system. They were acting more like the paid workers that they were, putting professionally necessary limits on their commitment.

It has been pointed out already that professional workers who care for members of their families have greater insight and understanding than their professional training gives them. From her experience of looking after her own father, who shared a bedroom with her young son, a social worker developed a critical attitude, which she tried to keep under control, towards relatives who 'don't try'. She had not found her own family very supportive, but they could not see themselves taking on a commitment similar to hers. As a hospital social worker, she found herself working with people whose normal reaction was, 'she can't come home, can she'? Families were shocked to discover that the hospital was planning to discharge old people, whom it would be very difficult to care for outside.

The widespread assumption of people working in the caring professions, and those caring for members of their own families, was that the NHS would take over. We know that health and social services find it chronically difficult to be responsive to need, probably because they define their programme in terms of bureaucratic necessity – the need to be consistent, to have a policy and keep to it. Perhaps we should ask what is the nature of the relationship between the client and the service being offered? These arguments may seem to lead to another way of responding to the problem – to see responsiveness to need as something that the voluntary sector is particularly good at.

Medical leadership

The diffuse nature of the health care of the elderly means that it is not possible to work on a task described simply as 'getting the patient better'. This raises anxieties in those involved about who is really responsible for care, often expressed as a) looking for someone who can really take charge and resolve the difficulties, and b) intense disappointment when such a person cannot be found.

The question of medical leadership needs to be considered. What is expected of the GP in the community and of the hospital based services?

i THE GENERAL PRACTITIONER

The general practitioner is consistently seen as the manager or coordinator of resources around the health needs of old people. This may seem an impossible role, one requiring not inconsiderable skill as a reticulist at the local level.

The GP is a figure of uncertain significance in people's understanding of community care. In theory, he is the gatekeeper to all kinds of services. It is likely that he will know the old person. He will be contacted by family or friends when mental confusion sets in. Not only is he able to make a diagnosis of any infections or other conditions contributing to the abnormal behaviour of the patient, but will advise the family on their best course of action. He may alert the community health and social services to the needs of the patient at home and, if necessary, ask for a domiciliary visit from the hospital consultant, who is the gatekeeper for further services linked to the geriatric or psychiatric services. In this way, the GP offers medical leadership in putting together a package of social provision. Often this happens, but it is unwise to expect the reality to always match up to the ideal. It may also be necessary to challenge the ideal itself, that the GP is best placed to initiate or coordinate the services. Complaints about doctors seem to stem from their being expected to live up to their own image of themselves as scientists with knowledge of physical disease. The doctor is asked two questions – what is wrong, and what are you going to do about it?

> The GP was no bloody use.

> He was very sympathetic but he said there was nothing to be done.

The GP is working in an area of professional uncertainty. If he says that nothing can be done he is only stating the truth according to his scientific criteria for effective action. He may then redefine his role to accommodate this area of uncertainty by involving himself in ameliorating the social effects of disease and debility in patients; or, he may attempt to back off from involvement with patients that he cannot help.

Some GPs who heard about this study wanted to talk about the problems they faced being asked to make non-medical decisions in working with elderly people. For doctors are confronted by familial expectations of what they ought to do. In a previous study I heard a GP talk of himself as 'the nut in a nut-cracker'.[34] Members of the family want him to confirm their diagnosis - that the patient is too ill to stay at home; but he is only a gatekeeper to resources through processes of referral. He does not manage resources for continuing care himself, except of course the support that he can give to the patient and to the family at home.

One doctor described his own reaction on visiting a patient.

> I went to see this old lady. I was shocked. She was living in such squalor. Her daugher lives next door. I don't know how any daughter could allow her to be like that.

The patient was 80 years old and her mental confusion was recent. At that stage – before he had been able to talk to the daughter – the doctor's assumption was that the family was rejecting.

> I won't challenge the daughter about her involvement. I won't have to. Faced with a doctor, people feel guilty and seek to justify themselves.

The doctor talked of rejecting families but in discussion it was much more difficult to explore how doctors – like other professionals – may also be seen to be rejecting. Those looking to them to resolve a situation do not distinguish whether they are unable or unwilling; they only experience rejection – seemingly, a moral authority is abandoning its own responsibility.

What happens when GPs do not act as gatekeeper to other services?

> A lot of people are just told your mother has senile dementia and there is no cure.

> We are in that situation. My husband is seventy and has arthritis. My mother lives with us and has been hallucinating for 3 years. I am on tranquillisers and anti-depressants. Our GP is desperate to get mother away for a week or two. The geriatrician says it's not his responsibility, it's the psychiatrist's. The psychiatrists say it is up to the geriatrician. We are left in the middle, we are despairing.

> GPs need educating. Mother became confused one night aged 68. The GP said it was old age. We got no information. My sister found out about making lists of reminders and having a clock for her to refer to. Shortly after, she went to the neurology department and then we saw a social worker. We are saving the social services and health services money looking after her. We don't mind because she is our mother but we need help and support.

Comments about doctors are sometimes highly critical in retrospect. They indicate the doctors' impotence, rather than their incompetence in the face of degenerative disease.

ii OLD-AGE PSYCHIATRY

The plea to 'give us a psycho-geriatrician' is one that some psychiatrists have been responding to; in doing so they are accepting an overt leadership role in relation to community resources.

> Psychiatrists are increasingly being drawn into the care of old people with mental disorder, not only by virtue

> of necessity but also out of interest. Specialist psycho-geriatric departments are being created throughout the country, albeit unevenly and with scanty resources, headed by consultant psychiatrists with a special interest in the elderly. The functions of these consultant psychiatrists in addition to the fostering of good clinical care of individual patients involved the giving of a lead in the development of facilities and in the integration of services. They must regard their task as being primarily outside hospital and as encouraging the various health and social services agencies to work much more closely together than they do at present.[35]

A psycho-geriatric panel meets fortnightly with the objective of keeping elderly people in the community as long as they want to be there. The work has to be limited to those at the greatest risk. The panel includes a psychiatrist and a geriatrician as well as a nursing officer, home help organiser, occupational therapist and the principal officer responsible for residential care in the social services department. As a social worker associated with this project commented, this experiment has to overcome the objections of the GPs who feel that their work is being scrutinised.

In the way geriatricians have, of necessity, developed an expertise in the management of the rehabilitation of hospital patients, psychiatrists with a special interest in the elderly are taking further a very difficult role in developing collaborative practices among services that are traditionally fragmented.

> The close working relationship of the various professionals involved in a case is as necessary outside the hospital as it is inside. The relevant colleagues are the general practitioner and his team and the involved members of the social services department ... Building a good working system is a slow process and involves a re-examination of some practices which may seem self-evident and immutable within a single agency. Nowhere is this truer than in the tradition of restricting the records of one agency to its own staff. This makes no sense in multi-disciplinary working except where there are conflicts of interest or where the patient/client specifically forbids the sharing of access – both events which are in fact exceedingly rare in this age group.[35]

If this problem of confidentiality is to be overcome, many doctors – and social workers – will have to re-think their relationship to patients and clients. A multi-disciplinary team that walks together on a ward round and talks together in a case conference is one thing: the new working relationship that is now being suggested is a network activated by a key worker of any discipline. More than one doctor enthusing about multi-disciplinary working has been known to talk of 'my team', a form of proprietoral interest that would be much more difficult to sustain in a community-based psycho-geriatric service.

The appointment of psycho-geriatricians or specialists in old age psychiatry is important because it is another exercise in our expectations of medical leadership. In one health authority, the debate around a proposed appointment focussed on two arguments.[36]

1. From the health authority: 'The development of this service remains one of our highest priorities. Nevertheless, you will be aware that the consultant appointed will have to have the backing of staff and resources if there is to be any notable impact on a great problem. It is anticipated that at least 10 assessment beds will be required, preferably within a district general hospital with perhaps 35 long-stay back-up beds (at the psychiatric hospital). In addition, a day hospital for 20–25 patients will be a necessity. The revenue cost of establishing the above service could be of the order of £500,000 per annum and in the present financial climate cold only be found by economies elsewhere.'
2. From the local authority: 'If a consultant psychiatrist for the elderly was appointed immediately, he would be able to work alongside existing consultant staff in a wholly complementary way and where resources are needed, the psychiatrist would be the person to specify what is required for the particular health district and to lobby for such provision.'

The local authority seemed to be asking for medical leadership in the development of services.

> It is wholly unrealistic for this essential appointment to be delayed until some halcyon period when the health authority is able to provide £500,000 in resources to establish an ideal level back-up support and quite impractical to expect the different disciplines to volunteer the redirection of resources in the scale without some basis for the service already being in existence.

The complaint about absent leadership is explicit:

> It is necessary for the health authority to take the lead in mobilising the necessary resources and this appointment would be an important first step.

It is as if the appointment represents an extra resource for social services and a deprivation of existing health services. The hope is that medical leadership will, in some way, help to integrate the day care and community support of dependent elderly people.

Another psychiatrist has described the shift of attitudes in setting up a community-orientated psycho-geriatric service.

> The departure was from a mainly medical model according to which people suffered from disease due to changes in brain structure and amine metabolism to a problem-orientated social model, whereby people had difficulties in coping with the life situations, because of the disabilities engendered by old age. The focus of therapeutic activity was shifted from an exclusive concern with the patient to include his physical and social environment. The emphasis therefore was not on intensive initial treatment followed by decreasing levels of follow-up and discharge, but on the evolution of a caring network around the patient whose interventions would have to intensify with time.[36]

It has been argued that the constraint on leadership may be a lack of adequate hospital resources – in particular, acute assessment beds – to make the appointment viable. But the same psychiatrist has questioned this assumption.

> The three reasons justifying psychiatric hospitalisation are treatment, assessment and holiday. Yet none of the treatments carried out require hospitalisation. Drugs or

> psychotherapy are as effective in the home as they are in hospital and ECT can be done on an out-patient basis. Assessment is best done in the home, where past memory traces are intact, rather than in the frightening, confusing and regression-inducing setting of a hospital. A psychiatric ward is hardly a place for a holiday and the relief for relatives can be more safely achieved through Part 3 placement.[37]

These thoughts, exciting and even radical, have to be put beside the expressed wishes of those who are looking for a psycho-geriatric service to which patients can be referred for assessment in the hope that they will then be hospitalised. The psychiatrist operating a social model of care has to be aware that he is undermining the motivations of many of those who are shouting loudest for his services.

Conclusion – familial conflict and networks of care

We are haunted by what Neil Smelser has described as the 'ghostly model' of the Victorian family.

> There lingers an often unspoken but nonetheless profound sense that what has happened to the family in the past century is unfortunate. It has disintegrated and fallen from grace and the yardsticks by which that fall is frequently measured are Victorian stability, solidity and serenity.[38]

And yet in one respect, roles within the family have become less segregated, partly through the redistribution of its income.[39]

If we phrase the question right, it is possible to get almost unanimous support for the notion that the family should care for its members. Generally, it is agreed that the family is an effective social system within which nurturing, mutual aid, daily maintenance and crisis management are all functions of the familial bond. However, when this familial bond is confused with what is expected of health and social services, it is necessary to argue for collaboration, as in the discussion document *Collaboration in Community Care.*

> If it is accepted that community care includes both formal care (by statutory and voluntary agencies) and supported

> informal care (by friends and relatives) and both residential and domiciliary care, then the network of support is very complex. It suggests that a great deal of coordination among individuals and organisations will be necessary.[1]

Today's idea of 'network' largely stems from a social anthropological study of the family by Elizabeth Bott. She concluded that a social analysis of familial roles had to take account of psychological need which allowed for differences of expectation.

> When the immediate social environment is a network, not all the people the family knows interact with one another. A considerable variation in norms and ideology is likely to arise. The greater the amount of such variation, the more difficulty people are likely to have conceptualising norms as a simple set of unambiguous rules. At the same time, the greater the variation in behaviour of norms and ideologies internalised from other people, the greater is the opportunity for reinterpretation and reordering of internalised standards in accordance with personal needs. This personalised version can be applied not only to oneself but also to other people and one has considerable choice in selecting and constructing the reference groups to whom it may apply.[40]

Judgments about what is the right thing to do become more complex as familial expectations become diffused in the wider social organisation of networks, including those whose job it is to work with families.

We tend to make enormous distinctions between formal care systems in the health and social services and informal care by relatives and neighbours. Some of these distinctions are valid, but not all. Distinctions are used to maintain a differential status which is totally in the interests of the formal systems. Having a professional identity requires the worker to look for opportunities to demonstrate skills associated with that identity. The more specialised the skill, the more evident this is. Doctors, for example, may get restless if they are unable to do things that their training and salary and status have led them to expect of themselves. Geriatric medicine, for good reasons, is in the van of promoting a more holistic view of treating patients. Nevertheless, a hospital geriatric department is working within a system geared to efficient working with patients. Other specialists refer patients to the geriatrician in order to unblock beds. Geriatricians are concerned with 'getting people better', in the sense of improving, or at least stabilising, their physical well-being. This is an example of the difference between formal and informal care systems. Formal systems have limited resources, the most precious being time, while it is assumed that informal carers have all the time in the world.

The professional and the informal carer work to quite different assumptions about the nature of care. The professional sees it is an exclusive judgmental purposeful activity – although it can be argued that a whole new profession of 'communty work' was developed to counteract this view. In contrast, it is assumed that informal care can be done by anyone. No standards have been laid down and not only is the outcome uncertain there is no obvious reward and the carer has no clear idea why he is doing it. Carers have begun to challenge these assumptions.

Meanwhile, other services have been notoriously slow in taking up the challenge, because they fear their work is ineffective. According to the ideal, the care of mentally frail edlerly people should be achieved in a way that uses the full potential of all the participating parties. Doctors would make diganoses and lead multi-disciplinary teams. Social workers would make assessments; community nursing services would carry out treatment; day centre staff would welcome clients independent and gregarious enough to enjoy their services; the family and neighbours would do the practical caring. That this does not happen in a smooth and autonomous manner is no more remarkable than that there are conflicts of interest inside the family. These conflicts are projected into the wider system of care, of which the family is only a part.

Within the wider system the conflict rages about who is responsible. Social services struggle to meet their statutory obligations and, even more so, to meet societal expectations, not only towards old people but, more especially, towards children. Some families have their social worker, many more with mothers looking after small children have reason to think well of their health visitors. Of course there are social workers who specialise in work with the elderly, just as there are geriatric health visitors, and the family doctor receives special payments for elderly people on his list. But those who take a special interest in the needs of the elderly do so without expectation of their professional reputation or status being enhanced. In this they are like the family member caring for an elderly relative. The rest of us are relieved, even grateful. Traditionally, however, these people feel exploited and misunderstood rather than appreciated as significant members of the community. This lack of status for what is essential, stressful and difficult work, has been complained of by geriatricians, slighted by their illustrious colleagues (though times change: there are now two or three professors of geriatric medicine) and by social workers still living with the reputation of the old welfare departments before 'generic' social work was supposed to make all clients equal in the eyes of the intake team.

Decisions about the care of mentally frail elderly people are essentially attempts to resolve a conflict of interests. The conflict centres on the relationship between the elderly person and the caring relative and is paralleled by the conflict between the various agencies that provide care for the elderly. This is not to say that these relationships are characterised only by conflict, but that the conflict will have to be contained if the relationships are to survive. The conflict may be more apparent than real, depending on one's point of view, but it has to be worked out nonetheless.

Part 3

SUPPORT AND TRAINING FOR COLLABORATION

Facing the difficulties

Collaboration will work where people have sufficient autonomy in their working roles and the freedom to be interdependent.

We know that collaboration does not always work and sometimes has the opposite effect to what is intended. A recent study of an inner city partnership programme describes how the philosophy of partnership draws attention to conflicts within the voluntary sector and between voluntary organisations and the local authority.

> The co-existence implied by 'partnership' has .. revealed a variety of perspectives on organisational goals and responsibilities and the existence of enhanced resources has led to a heightening of inherent tensions between the voluntary and statutory sectors.
>
> At the level of the individual voluntary organisation, the major preoccupation has clearly lain with the need for Partnership structures to ensure the acquisition and defence of a predictable and orderly resource flow. The pursuit of this limited operational goal concerned with the organisational survival has governed the relationship of individual groups both with other voluntary organisations and the CVS and has led to competitive strategies that have created internal conflict.[41]

It seems there are sound reasons why collaboration in community care cannot be easy. If collaboration is defined as working together across the boundaries of profession and agency, it has to be recognised that these professional and agency differences are there for a purpose. They allow for the development of specific expertise, discrete tasks, and the mechanisms of monitoring and accountability. After all, that is why health and social services are always being organised and reorganised; why housing departments are separate; and why voluntary organisations are as competitive with each other as they are suspicious of the statutory services. Collaboration can be an uneasy mode of coexistence. In order to recognise each other's existence, there must be mechanisms to exchange information and develop non-aggression pacts. Intermediary bodies, as their name suggests, may be expected to mediate but lack the authority to do so.

A voluntary organisation worker, critical of the work of another organisation, sought an unofficial interview with the director of social services. The worker was seriously concerned about the activities of workers in the other agency which affected the interests of elderly people in the community. Confronting the other workers had not resolved the issue and it was difficult to decide how to take things further, especially as both organisations would be looking for further funding from the local authority. The suggestion that the CVS might be involved in order to settle the dispute was though incredible and met by this worker with a grimace.

In what sense is it to anyone's advantage to maintain or assume ignorance of the other person's point of view? Ignorance can be used to project feelings of incompetence onto other people. Even good-natured abuse – 'they don't know their arse from their elbow' – can be a substitute for constructive thinking about how one person can help another by being involved with them.

Health and social services face continuous, insatiable demand. Day-to-day management is not concerned with the higher reaches of medical science or social work theory: it is about unblocking beds and reducing the pile of unallocated cases. The statutory services suffer most, because they are obliged to try to make their services available to everyone according to need. Voluntary agencies can be more selective about using their resources in order to get good results.

Researchers at the National Institute for Social Work have devised a tongue-in-cheek guide for managers of scarce resources – not a recommendation, but a list that might explain how social services behave:

1 Delay seeing people of low priority.
2 Define the problem in terms of the resource you can most easily mobilise.

3 Don't spend time dealing with conflicts.
4 Discourage referrals for which your concrete services seem irrelevant.
5 When a scarce resource is requested, offer another which is less scarce.
6 Limit your relationships to the most obvious participants in each case.[42]

There are a number of good arguments why managers in health and social services and the voluntary sector may be wary about collaboration.

1 It deprives people of their usual defences against working too hard. People have to put limits on what they can do. If they feel under pressure already, they cannot be expected to take an expansive view of their responsibilities.
2 It undermines the confidence of managers that they can manage properly.
3 Collaborative practices are not easily replicated. People emphasize personal factors more than role expectations in analysing collaborative relationships.
4 Collaborative projects are difficult to evaluate. Measuring quality of service will isolate certain factors in the way that different agencies take up aspects of the work. Many of the advantages of collaboration are likely to be different from the outcome expected by the participants. Evaluation is from a single point of view and more easily applied to the work of a single agency.

However, there may be advantages if collaboration means access to other people's managers.

> If I have a problem, I go straight to the Director [of Social Services].

This statement by a worker in a voluntary organisation would sound tactless to many local authority social workers, who rarely see their director and suspect that he knows little about them as individuals. Collaboration relieves the isolation of the manager at the top by making informal contact possible outside the system. He can keep his ear to the ground without having his head stepped on.

Relationships which may not be easy or possible in hierarchical organisations can be explored on the neutral ground of a collaborative project. Working in a structured environment, which gives them the defences they need in their working roles, some people find these defences confine them and limit their opportunities for experimentation and learning. They benefit from the good informal working relationships with senior managers in the statutory services that are possible in a collaborative project. In a sense, people are having their cake and eating it.

In their study of social service departments, Ralph Rowbottom and his colleagues at Brunel University argued that the question of professional freedom of the social worker is not between complete autonomy and complete bureaucratic control, although people may think it is.

> The issue is not whether the social worker should be or even is allowed a degree of discretion. The issue is whether the discretion allowed is delegated by those who are accountable for how it is exercised or whether the discretion allowed is within some defined and inviolate area which is the professional worker's own by right.[43]

Such delegated discretion is constraining on the professional autonomy necessary for collaborative working. However, we have seen how statutory services can combine with the voluntary sector in developing small scale initiatives to promote community care; for example, day centres staffed by volunteers. These are the kind of projects that cost little, look good when written up, build up experience which should make them easily replicable and yet remain thin on the ground. This kind of collaboration can be difficult to sustain. I heard this frustrated from a worker in the voluntary sector.

> We couldn't get social services to live up to their promises. They were supposed to give us a worker but there wasn't one. We have been trying to make ourselves independent of them. Meanwhile, they go around being proud of what they have done.

The voluntary organisations and social services need each other but it is not always clear what they need each other for.

The partnership can legitimise the work of the voluntary organisation, giving it quasi-professional status in an area of work where few bids are being made for professional competence. Workers in the voluntary organisations express their feelings towards social services in an ambivalent way – emphasising the personal competence of individuals rather than the value of the service as a whole. Contempt is obvious when the service does not deliver the goods, feelings that are remarkably similar to those of informal carers when they are disappointed. The success of voluntary organisations in identifying the needs of informal carers and adopting an advocacy role for them, must have been helped by this common attitude towards health and social services. In their own ways, they are both clients of a management system for resources that deal with elderly mentally frail people. The challenge is to find a way to feel part of the system without simultaneously feeling a disadvantage as clients.

David Gilroy has outlined some of the applications of informal care.

> The dangers of the 'formal' sector invading the 'informal', appropriating its assets and then promptly bureaucratising them, are all too evident to be ignored.[10]

Gilroy suggests one way in which over-bureaucratisation may be resisted. Drawing from a study by the Equal Opportunities Commission,[20] he suggests that the formal services are so stretched by the efforts to meet the needs of those who lack informal care that we need to look more at the contribution that can be made by mutual aid groups to support those who care intensively for highly dependent people, but such mutual aid groups also need support from our statutory and voluntary organisation. Informal carers are ignored, are invisible, or else the formal services start to feel responsible for them.

Informal carers do not have the same defences as social workers who are able to limit their relationships with their clients by using organisational practices a a defence against what might become an insatiable demand. A social worker wishing to have a different kind of relationship with an informal carer will have to relenquish some organisational defences and accept the frequently painful experiences of the carers. The worker will draw on his individual defences – his feelings as an ordinary person – while allowing the association with guilt that goes with the social work role.

In thinking about how to manage guilt, we have to look at the relationship of the individual to the organisation. Workers with the mentally frail elderly may even find themselves isolated in their own agencies, because of the uncomfortable feelings that they bring with them.

Projections of inadequacy have to be accepted by any system of care, as receptionists in a GP's surgery or a hospital clinic know. Where patients or clients are anxious, they are angry at those who fail to protect them from their anxiety. The cause of the anxiety becomes the fault of those who are unable to give relief.

The reason that old people so often suffer from being 'too frail and too fit' – too frail for one service and too fit for another – is that services are designed according to criteria of fixed need, determined at the time of entry into the system. This is true of any service for which there is a process of assessment as a condition of entry. The relationship between different kinds of provision, for example sheltered housing in old people's homes, is often a struggle to maintain a principle of mutual exclusivity in provision for people whose needs are changing all the time. Thus, sheltered housing units may be intended for people who are capable of looking after themselves but find it hard to cope with their present homes. A report on sheltered housing stated:

> All tenants are expected to be independent and able to look after themselves, perhaps with the support of friends and relatives. The warden will not always be available to answer calls, so this element of independence is very important.[36]

The role of warden is open to wide interpretation. Like families, wardens find that the people in their care become more demanding. Unlike families, wardens have job descriptions, but these do not stop the expectations that others have of them from rising inexorably to meet the need.

In one local authority, nine percent of the tenants in sheltered housing were thought to require a higher level of support. The report said that in some ways they 'matched the ideal but outdated profile of the inhabitants of Part 3 accommodation'. Looking at old people's homes, the report found that their residents were also more frail and dependent.

> A large proportion of physical, mental and social handicap described confirms the subjective views of staff regarding the growing number of people in the homes with these problems. It can be seen that a very high proportion are aged 80 plus and that there is an equally high incidence of physical and mental infirmity. Problems of incontinence and confusion cause management difficulties and necessitate relatively high staffing ratios and 'nursing' attention for a number of residents. The typical profile here is of high dependency, great physical difficulty and restricted capacity for normal social interaction. Many of the current residents of old people's homes might have been long-stay geriatric patients in a hospital ten years ago.[36]

There is a fateful logic to these arguments: the principle of progressive dependency, by which systems of care on their own inevitably find themselves looking after more dependent people than they originally set out to help.

This local authority decided to make special provision for the elderly mentally infirm.

> The integration of such residents in ordinary OPH accommodation is a source of much discontent and unhappiness to other more mentally healthy residents. In order to offer the 'best' service to all residents, the setting up of a 'special' group in an established OPH has been necessary.[36]

They also went further and planned a residential unit exclusively for elderly mentally infirm people.

Thus, one response to the tendency of old people to have increasing needs is to plan a graded series of provisions, stepping stones from total autonomy on one side to total dependency on the other. It is an attempt to match people and resources in a consistent way and it is attractive – in theory – not only to the planners of resources but to those who have to work in these systems of care, like the wardens in sheltered housing schemes, because they know what they ought to be doing. But it is equally frustrating in practice, when highly dependent elderly people are not very good at using stepping stones.

This kind of linear progression in planning services is unlikely to work without some integration with a collaborative, and therefore temporary, task system around the individual. However, the two kinds of system work on quite different principles. In the first instance (Figure 2), the services available are constant and the old person moves among them. In the second instance, (Figure 3) the person is assumed to be constant and the services are moved around in order to achieve some consistency in support.

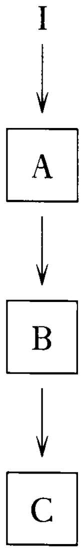

Figure 2

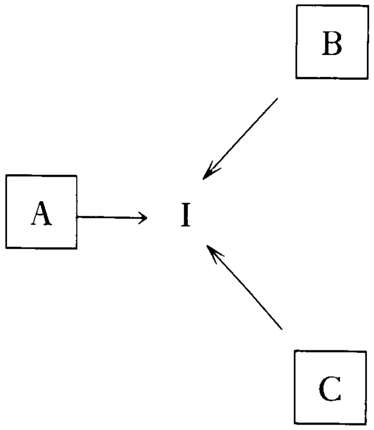

Figure 3

It is a truism in these days of welfare pluralism to argue that the formal systems of care in health and social services are, or should be, supportive to the informal care that goes on anyway in the community. This may be so when informal carers are seen to be part of the client system. Formal agencies know how to work with clients. It is more difficult, though, to take account of informal care as a resource. The work that has been done on relatives' support groups has been an important development in the emergence of informal care as are source of self-help and mutual support. The successful launching of the Association of Carers has served to establish carers in their own right, not as lonely extensions of their dependent's debility.

The organisation of informal care is very different from that of formal organisations. Some researchers in the US, drawing on experience of self-help groups in Boston and Washington, have outlined good reasons why this should be so.

> First, human services agencies are governed by a view of self-interest, professionalism and autonomy. They guarantee a kind of degree of competitiveness within and among agencies that is wasteful of existing and potential resources. Second, the ideology of these agencies together with that of their funding sources reinforces a pattern of incentives and rewards that in practice works against re-definition of roles and resources. Third, although there has been recognition that resources are limited and that better and more co-ordination among agencies is essential, efforts at change have been remarkably unsuccessful. Fourth, human services agencies, by virtue of their history and clinical orientation, are deficit oriented, not asset oriented, in regard to their clients as well as to the utilisation of non-agency personnel. Fifth, informal processes and relationships among agencies that threaten existing boundaries and structure or that cannot be controlled or judged by the usual ties between accountability and the calendar, are looked on with suspicion and hostility.[44]

A social worker with a special interest in the elderly wanted to set up a local committee to manage a paid good neighbour scheme and other initiatives in support of elderly people in the community. With her senior social worker, she was discussing how a social services department might support this initiative. The department's problem was how to be accountable for an enterprise with which it was associated. In this sense collaboration at ground level was seen to be threatened by lack of support from the hierarchy. The area manager had sanctioned the work but the senior officers, assistant director and above, were, it was thought, being subjected to political pressures from a council suspicious of voluntarism. The social worker was looking for ways of setting up a local committee which would not involve – and therefore probably antagonise – a bureaucracy with formal political accountability.

These social workers were finding out when a local initiative might or might not have to 'go public'. They had been successful in placing individual elderly people with foster families and they 'went public' then – the individual cases became a project – in order to recruit more families to the scheme. The good-neighbour project had not yet gone public in the same way, although there were one or two examples of 'good neighbours' being recruited through tenants' associations and being paid for out of the attendance allowances of elderly people.

Would it not be possible to use a voluntary organisation as umbrella to this initiative – an orthodox, even traditional, way of statutory services making community-based projects viable? The social worker initiating the project was frustrated in two ways: first, she suffered from a controlling hierarchy which inhibited non-accountable activity and, secondly, she was wary of a voluntary organisation which would take over her 'neighbourhood-care' scheme once it had been set up. Its organiser was thought to be over-friendly with the director of social services.

This image of the 'take-over', suggestive of commercial practice, implies that community care is subject to the rules of the market place. The social worker wanted to distance herself from her own bureaucracy with its accompanying political accountability. If local initiatives to implement a 'resource exchange network' have to be owned either by the statutory services or by an established voluntary organisation, which values its close working relationship with the statutory services, we may have to agree with the American analysts that informal and formal organisation around the needs of dependent people in the community have contradictory objectives.

Everyone says that collaboration is a good thing in principle. For those not being specially collaborative in practice, the reason given is very likely to be the issue of confidentiality. A psychiatrist of old age, commenting how often different agencies work with old people independently of one another and without pooling information, suggests that, although confidentiality is given as a reason, 'a far more likely explanation is an unthinking and compartmentalised approach – an expensive and sometimes dangerous waste.'[35]

This psychiatrist has developed a multi-disciplinary team of doctors, nurses, occupational therapists, social workers, psychologists, and ambulance drivers.

> While each of the disciplines has its specific function, there is much blurring of roles, particularly in the management of patients who are not in hospital. Much of the work involves human interaction and is within the competence of professionals in the team. In most cases, the prime worker is designated on the basis of personal preference and availability rather than profession. However, each professional within the team is primarily responsible for liaison with colleagues of the same discipline outside the team.[35]

This is a model of internal heterodoxy and outward orthodoxy. The advantages of inter-disciplinary working are protected within a team, where a common policy is practised.

It is tempting to suggest that the multi-disciplinary team depends for its cohesiveness – at least when set up – on the leadership of the medical consultant, but it is probable that it can only be sustained if there are corresponding changes in the structures of external authorities. To break down the confidentiality/secrecy of other agencies is more difficult than changing working relations with colleagues. There are ethical and managerial problems to overcome, which may not even be thought worth tackling if they threaten the professional autonomy of different disciplines. People are wary of working across professional boundaries for fear of criticism from other disciplines. The fear is expressed most obviously in anger. I heard the following comments from the conflicting viewpoints of a GP and a social worker:

> My duty is to my patient and I have no time for people who do not understand that relationship telling me what to do.

> You can't get hold of the GP, and when you do you don't get a civil word.

We have observed that some voluntary agencies are suspicious of statutory services and act as advocates to protect the rights of their clients. In return, some professionals distrust the patronising attitudes they detect in the voluntary agencies. Is it not possible that there is some mutual projection of feelings of inadequacy and omnipotence?

Health and social agencies trying to work together to provide an integrated system of care have to deal consciously with these problems. People working in agencies suffer from those clients and patients who often have extreme feelings about their services, denigrating them as useless in the main and directing their positive feelings towards individuals in agencies – the voluntary organisations for example – whom they see as carrying the attack to the services which have failed to satisfy their needs. Workers in the different services also turn on each other. Because they feel associated with the uselessness and hopelessness of dementia in old age, they try to defend themselves against these feelings by seeing other services as useless and helpless.

The organiser for a project supporting elderly mentally frail people in the community was supported by two voluntary organisations working with the elderly and the mentally ill. The organisations shared premises and had good working relationships but their management committees were thought to maintain traditional rivalries and suspicions about what each organisation was doing. Funding for the project came from three sources, one for the organiser's salary and the others for the day centres he was helping to set up and support. He saw his own support as fragmented and uncertain. A social event he organised for the management committees was disappointing. Those that came did not seem to want to talk to each other.

Taking an interpretive stance towards the provision of care for a very dependent group in society can leave the worker, as in this example, feeling isolated, pulled in different directions, and perhaps sharing some of the emotions of informal carers.

The problem of institutional splitting as it affects the worker in social services, has been described by Janet Mattison and Ian Sinclair.

> The disquiet roused by the bad or sad things which have happened between clients is easily relieved by an attack on other workers, which, in its turn, invites a response.[45]

Sally Hornby has identified one of the main hindrances to collaboration as the misuse of professional and agency boundaries for social defence purposes. She defines collaborative practice as an expertise in working across professional/agency/group boundaries, requiring specific knowledge, understanding and skill. Recognising that hindrances to collaboration in the structure of the agency help to determine the level of work possible for the practitioner to function, and that other hindrances arise from clients whose internal problems may be externalised and find their way into relationships between workers, she is especially interested in the hindrances to collaboration which originate in workers themselves.

> If field workers could identify with a practitioners' network in addition to their profession or agency, it would facilitate integration of services and social care planning. The latter task required ability to use a helping network based on a neighbourhood and/or client category (such as the mentally ill). A practitioners' network would embody the formal sector of a helping network.
>
> Identification with the network would encourage fellow feeling, thus reducing the likelihood of agency boundaries being 'snarled up' by social defence projections. It would encourage a reappraisal of professional roles and their inter-relatedness. Who has not participated in meetings where several professionals arrived assuming they are the most important worker in the case? In how many others are these assumptions never uncovered?
>
> To build up a network system with which workers can identify is a formidable task. Agencies develop their own collaborative links through liaison or support groups, but the concept of a practitioners' network is fundamentally different: it is not agency centred but client category or neighbourhood centred. To create such a network, day to day collaboration, though highly valuable in forging links

between particular practitioners, is insufficient. Interdisciplinary teams are also valuable but the model is inappropriate to a large and loosely knit system.

I suggest that it needs a few experienced practitioners, authorised by relevant agencies, to meet regularly; not primarily to act, but to discuss developments in collaboration and explore boundary problems. Given sufficient commitment to the task, group cohesion could be achieved on the basis of a network identity. This would form a core group, which could provide an infrastructure of trusting relationships to underpin and facilitate collaboration of other workers. It might foster a larger group with which others could also identify.[46]

A worker in a voluntary organisation discussing two different kinds of provision for elderly people in the community, a self help lunch club and a fostering scheme as an alternative to institutional care, identified three sets of criteria for thinking about the division of labour between statutory and voluntary services.

a) the pragmatic; is it easier to fund a certain project this way or that?
b) the task-focused; is the work better done by a social worker, say, or a volunteer?
c) the ideological; is this the sort of thing that the statutory or voluntary services ought to be doing?

A social worker and a psychologist have been working with a voluntary organisation in developing group work with the carers of elderly mentally infirm people. They seemed to make a good team but the 'professionals' had very different ideas about their relationship to the voluntary organisation workers. The psychologist argued that the work belonged to the voluntary organisation and that they attended to help as they could. The social worker thought the opposite – that it was their work and the voluntary organisation workers helped as they could! The social worker had some doubts about the competence of the other workers and thought that their organisation tended to infantilise old people and have a controlling attitude. This was more than a theoretical discussion;

it had implications, for example, on how the work was publicised and referrals encouraged.

This social worker has been linking with other social services' specialist workers with the elderly. She is aware that they are anxious about their status and are looking to each other for support rather than making links with other agencies. She is working to further establish the professionalism of social work with the elderly and is unlikely simply to take a critical stance towards other workers but to think that their influence is important. The psychologist is able to take a more relaxed view of the inter-dependence of voluntary and statutory workers because, as the social worker suggests, his role in the hospital system has given him greater experience of working with other disciplines. As a professional, the psychologist has been working in the community. He takes a positive interest in the voluntary organisation and is on its management committee. Ironically, he now finds that as hospitals become more 'community oriented' he is expected to work more in the hospital!

Both workers are constructing in their own minds different organisational vantage points around the concepts of professional identity, community involvement and (for the workers in the voluntary organisation) representation of a client group in relation to health and social services. In each case they are trying to construct a system that will satisfy their needs as workers. This is not of course a selfish approach. If they are unable to find a way of satisfying their needs while helping elderly mentally infirm people, they will begin to define their work in a way that will exclude their client group. We have seen how workers have found a way or working with mentally frail elderly people by relating to their carers. They are likely to become competitive and possessive about the gratifications associated with their work.

Collaborative working, having extended the limits of altruism, is also subject to conflicts of interest – caused not by indifference but by concern. We have to try to understand why collaboration is theoretically so important and practically so difficult to achieve. Belief in collaboration expresses a wish for cohesiveness, based on the assumption that we are all working towards the same ends. In health and social welfare this is often expressed treating or relating to the 'whole person'. To work with someone in an isolated partial way is seldom admitted by anyone, yet we criticise others for doing so. Who would argue that professionally he was not interested in the whole person, only in the bit that he could do something about?

The theoretical importance of collaboration is part of the mythic structure of society, in which the 'average' family may in fact be atypical and concepts of neighbourhood/community/network and so on are an attempt at clustering of variables in loosely defined sets. Thus we try to impose meaning on the world through our observations of its apparent cohesiveness. A criticism of the Barclay report has been that it assumes informal care is more robust than some workers have experienced it to be.[47] The researchers who showed how scare resources may be managed, (page 78) have also drawn up a guide for the discovery and creation of resources.

1 Respond quickly to a request for help.
2 Define problems in as many different ways as you can.
3 Work with conflicts.
4 Encourage early referrals.
5 When a resource is not available, try to create an alternative.
6 Perceive everyone as a potential resource (including the client) and become involved in the community.[42]

The individual and the organisation

How can people be trained to manage resources and respond to need? The challenge to the worker belonging to one or more teams or work groups within a wide-ranging network of everyone (professional or otherwise) concerned with the care of the elderly, is to take on a complex 'boundary role' in relation to small and large group behaviour.

> The large group is composed of individuals and of the small groups to which they belong. The small groups may be 'formal' in that their membership and purpose are consistent with the requirements of the enterprise; or they

> may be "informal", directed towards other ends. The individual may be related to the large group through membership of more than one small group. The internal life of the large group consists therefore of the relationship between individuals of the relationships within and between the groups to which they belong. Individuals have their own overt needs and unconscious strivings and small groups their tasks and assumptions which identify them and hold them together. Moreover, individuals and groups interact at conscious and unconscious levels and at work and assumption levels simultaneously.[48]

Training in collaboration is essentially training in group relations. In particular, there is a need to understand the psychological splitting and projection that is going on between and among workers in different agencies sharing a common task. Feelings of guilt heightened by a sense of impotence would, if uncontrolled, leave people unable to function properly. An essential defence against feelings of inadequacy is to project them in such a way that others are seen to be incompetent and uncaring.

Training for collaboration must help people to understand these processes and to counter the ill effects of conflict and misunderstanding.

When we talk about guilt in relation to the care of elderly people, we are describing an assumption of guilt. We are not thinking of actual malpractice or cruelty or deliberate neglect – though we know that such things happen. We are talking about behaviour which appears to be caused by those giving care also being responsible for the circumstances that made care necessary. Rationally, this is absurd. Nevertheless, we have to try to understand that it is a cause of anger felt towards people who fail to alleviate the symptoms of distress associated with debility in old age.

The relationship between formal and informal care systems is a minefield, where people are guided by personal values as well as agency policies. Some workers wishing for greater accountability to the community welcome the new legitimisation of carers as they emerge from what has traditionally been seen as a client system. Some voluntary organisations have attracted significant loyalty from carers and this has given them new authority in their relations with the statutory health and social services. But recognition of informal carers does not in itself contribute to collaborative practices.

Training people to work more effectively across the boundaries of their own agency, professional identity, or interest group, is very different from training which confirms them in their roles, professional identities and interest groups.

Training for collaboration is about relating skills and experience to the needs of a complex environment. How do 'problems' get isolated from, and integrated with, other concerns? The dual response to a person's need is first a wish to respond to that need, and secondly a realisation that the need is also a demand. The problem is perceived as what one person has got and the other has not, and then of what both are feeling deprived. The recognition of need is synonymous with a realisation that the need represents an actual or potential demand on a person's resources. This is welcome in the sense that it is then possible to think of making a transaction that would met the need, but is threatening if one's resources are depleted as a result. We have seen how limits are put on a relationship in order to have control over the transaction.

Mutual aid looks good, but we have to recognise why common sense is sometimes over-ruled by individual self interest – for reasons of unequal exchange, competing interests and problems of leadership and ownership. It is important that people should be able to identify with different sides of an argument; clients versus carers, workers versus clients and carers, the broad view versus the individual need, formal care versus informal care.

There are patterns of working relationships that inhibit workers in different agencies from being mutually supportive in their common aims.

1 Ownership of projects and overall control.
2 Accountability of project workers across organisational boundaries.
3 Competing community interests.
4 The legitimising of new initiatives that cut across traditional work patterns.

5 The defensiveness of workers against feelings of exploitation.
6 Lack of resources.

Community care may be seen as shifting the ground where care is provided, involving in the community the counterparts of those whose professional and occupational skills have been exercised in a hospital or institutional setting – notably workers in the health services and personal social services. But community care also means care by members of the local community, not merely among them. This involves families, friends, neighbours or volunteers, all working alongside professionals and, in some instances, instead of them.

Whereas an institution provides a limited physical setting for inter-professional or inter-personal relationships, the community setting can be seen as boundaryless, full of potential, but also frightening. At the same time, collaboration may be important in a positive sense, influencing the motivation and effectiveness of workers with disadvantaged groups.

1 A shared understanding with workers from other agencies of the needs of a client group can compensate for the low priority given by any one agency to this group as a primary focus of care.
2 Collaborative working has the potential to look at the real needs of people at risk in the community and to find appropriate ways of meeting these needs beyond the limited work of responsive agencies already overstretched in meeting their commitments.

Collaboration is well established as an idea in the minds of many field workers, especially those who are attempting imaginative responses to what is commonly accepted to be a growing problem. For the idea to be turned into practice, we have to look at the management and support functions in the collaborative process.

1 Managers with agencies preoccupied with the effective use of their own resources have to find ways of supporting workers who may seem to be diverting resources under the influence of other agencies.

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1 Managers with agencies preoccupied with the effective use of their own resources have to find ways of supporting workers who may seem to be diverting resources under the influence of other agencies.

2. Managers of collaborative systems of care – formally in steering groups and in other ways – have to represent these systems to their constituent parts.

Training for collaboration has to offer people the opportunity to examine the processes they are involved in while working across the boundaries of what often seem like different compartments in the systems of care. This would involve front line staff, middle managers (who may find particular difficulties in obtaining either an overview of services or a picture of the whole client), and senior managers. It is clear that the development of collaboration between agencies has to be sustained by a re-examination of roles within agencies.[49] Too narrow definitions of effectiveness and control could lead to those attempting collaborative working as being perceived as inefficient or deviant.

A two-day study group conducted by the London Boroughs' Training Committee on Developing Caring Networks for Elderly People and Their Families in the Community was oversubscribed four times. It was significant that people felt the need to talk as much within their own discipline as to work in multi-disciplinary groups. This training event, which attracted workers in health districts, also led participants to think of applying a similar model in developing a local forum for multi-disciplinary work.

> Forums may be of two kinds, formal and informal. The task of the formal forum would be to provide an opportunity for potential participants first to present evidence of their own needs and practice and also to create an interdisciplinary working spirit. Local authorities and health authorities have a requirement to provide community care and should give support to this kind of initiative. The forum should attract hospital consultants and junior doctors, GPs, community nurses including community psychiatric nurses and district health visitors, physiotherapists, occupational therapists, day care workers, home care workers, residential care workers. The transport section should be represented, as should voluntary workers. Social workers in hospitals and area teams would be involved. We have to persuade others that investment of time in, say,

attending a conference with subsequent meetings to take on issues raised, will pay off eventually, potentially quite quickly, by reducing time-consuming frustrations of ineffective communication channels and perhaps by preventing crisis breakdowns or unnecessary stress on workers and informal carers. We are all interdependent in providing a service, regardless of status.

An informal forum would be more case focused and would involve all those concerned with a specific case. Someone would be designated as taking a liaison role and these forums could then be a vehicle for involved professionals, families and neighbours. We do not think that these informal discussions would be reported back to the formal forum, though they would have its support. The forum could, however, receive case presentations which would fulfil an educative function and provide an opportunity for sharing problems and experience.[50]

The London Voluntary Work Development Centre – Advance as it is now called – is proposing a programme of group and organisational developments to work on issues of collaboration.

1 Role consultations with individuals with particular emphasis on issues to do with the representation of other people's interests.
2 Consultations with groups about the relatedness of internal and external pressures in their work.
3 Workshops where those working with inter-group conflicts may share their experience and develop their common understanding and collaborative relationship.
4 An experiential conference on working relationships in the community with participants from neighbourhood care groups, voluntary organisations and from health and social services. At the conference, people will have the task of exploring group relationships as they happen in the conference 'community' with opportunities to examine issues of authority and representation, including the ownership of political and cultural values.

This programme recognises that people need training to gain greater confidence in their own authority in working relationships. Collaborative working requires identification with a task system, transcending agency and professional boundaries. This allows for the sort of open negotiation – where no-one need be the loser – between worker and worker in different systems of care, and between worker and client. It is a way of working for which there can be little institutional support. The collaborative worker has to learn to work independently of residual loyalties to agency or professional identity, but in a way that is loyal to the task – while being aware all the time that the residual loyalties will remain.

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The limits of altruism explores the social and psychological processes which influence collaborative work. Starting with the elderly person in need and his or her relationships with informal carers, it goes on to examine the strengths and weaknesses in much existing support as reflected in the experiences of both service providers and users. Efforts to do better will raise important questions not only for voluntary and professional workers on the front-line but for policy-makers and managers in the health, social services and voluntary agencies concerned with community care. The text is designed to be 'worked at', not merely read. It offers an account of collaboration against which readers can assess their own experience; it is a stimulus for critical review and a resource for small group discussion, for example in the context of training initiatives.

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