Exploring the provision of services for older people living at home, this book examines the social context of old age, looking at structural barriers such as ageism, racism and sexism, poverty, and challenges the view that the increasing number of older people in the population is problematic. Moving from theory to practice, there is a discussion of issues such as day services for people with dementia, housing and support services, GP–social services collaboration and short-term breaks and how these are affected by the new emphasis on the choices of the service user. Finally, the work focuses on research into the development of practice through inter-agency collaboration, more skilful care management, 'specialist' teams and changing professional social worker attitudes to service users by empowering them.

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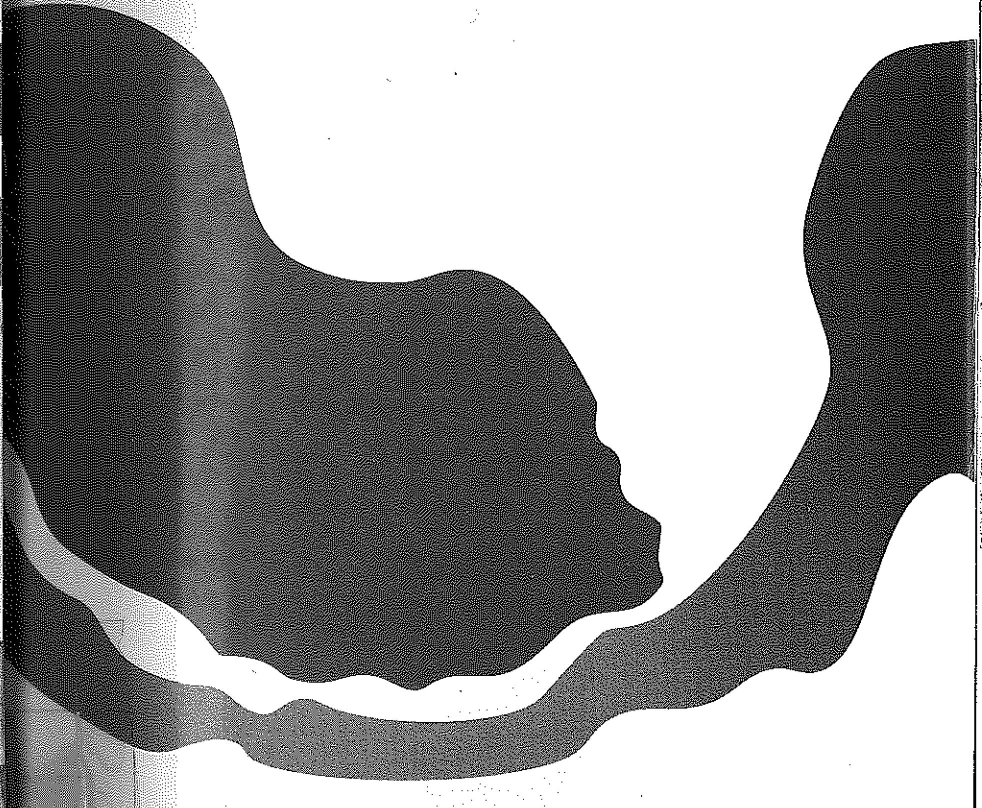
edited by Rosemary Bland



Highlights in Social Work 29

Chapter 1

The Social Construction of Old Age

New Perspectives on the Theory and Practice of Social Work with Older People

Chris Phillipson and Neil Thompson

Introduction

The impact of an ageing population has caused considerable debate and discussion over the past few years. These discussions have emerged against a background of rapid change in terms of the context of ageing. Three important features may be identified here: first, the growth in public awareness and interest in ageing issues – these sharpened by concerns over the ability of governments to provide financial security for future generations of pensioners (Phillipson 1991, Bengston and Achenbaum 1993). Second, in the case of Britain, the impact of legislation in the field of community care and the movement towards a mixed economy of care (Phillipson 1994). Third, the growth in early retirement and the evolving concept of 'the third age', this raising issues about changes in policies and attitudes to realise the full potential of later life (Midwinter 1992).

This social context of ageing has itself influenced debates within the field of social gerontology. In particular, in the 1980s an important theoretical debate emerged focusing on the social construction of old age. The themes associated with this perspective highlighted the extent to which the wider social and political environment influenced the lives of older people. This was analysed in terms of areas such as the production of poverty in old age (Walker 1993), in the development of ageism (Bytheway 1994); and the experience of marginalisation within the family and residential homes (Biggs 1993, Kingston and Penhale 1995).

In assessing the value of the social construction approach, this chapter will first, review some of the key arguments arising from this perspective; second, consider some implications for social work practice with older people; third, review some emerging issues in the study and experience of old age.

The social construction of later life

The social construction perspective was developed by a number of researchers during the late 1970s and early 1980s. The model grew out of the politicisation of issues surrounding old age, together with the problems faced by traditional theories in developing an effective response to the unfolding crisis in public expenditure. Early studies using this perspective included: *The Aging Enterprise* by Carroll Estes (1979); 'The Structured Dependency of the Elderly' by Peter Townsend (1981); 'Towards a Political Economy of Old Age' by Alan Walker (1981); Chris Phillipson (1982); *Political Economy, Health and Aging* by Estes, Gerard, Zones and Swan (1984); *Old Age in the Welfare State by John Myles* (1984), and *Ageing and Social Policy* by Chris Phillipson and Alan Walker (1986).

A general review of the arguments adopted has been brought together in a collection edited by Minkler and Estes (1991) entitled *Critical Perspectives on Aging*. Later studies influenced by this approach include those by Bernard and Meade (1993), Biggs (1993), Arber and Ginn (1991), Hugman (1994) and Biggs, Phillipson and Kingston (1995).

A major concern of these studies has been to challenge a view of growing old as a period dominated by physical and mental decline (the biomedical model of ageing). This model was attacked for its association of age with disease, as well as for the way that it individualised and medicalised the ageing process. The approach taken by what may be termed critical gerontology is a view that old age is a social rather than a biologically constructed status. In the light of this, many of the experiences affecting older people can be seen as a product of a particular division of labour and structure of inequality, rather than a natural part of the ageing process. Alan Walker (1980) elaborated this perspective with his concept of the 'social creation of dependency' in old age, and Peter Townsend (1981) used a similar term when he described the 'structured dependency' of older people. This dependency was seen to be the consequence of the forced exclusion of older people from work, the experience of poverty, institutionalisation and restricted domestic and community roles.

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The paradigm developed by critical gerontology is shared by developments in the study of other age groups. For example, many of the themes in the collection of essays edited by James and Prout (1991) *Constructing and Reconstructing Childhood*, explore issues debated in social gerontology in the 1980s. The connections between age groups have been further explored by Hockey and James (1993) in *Growing Up and Growing Old*. A central theme of this study is the extent to which power is lost and gained at different points through the life course, and the possibility of both young and older people being affected by processes of infantilisation (see further below).

In respect of social construction or critical gerontology, the main themes of this approach have been concerned with:

- Challenging a form of biological reductionism, whereby the real physiological and biological changes which take place with ageing are often used as a justification for denying old people the right to participate in decisions which affect their lives.
- Showing that age must be seen in relation to the individual's location within the social structure, including factors such as: race, class, gender, and the type of work (paid and unpaid) performed by an individual through his or her life.
- Demonstrating that later life is a time of reconstruction, with older people active in the search for meaning – through work, leisure and intimate friendships.
- That the lives of older people may be seen to be in tension with the nature of capitalism as an economic and social system, with the poverty of older people, their exclusion from work and their image as a burden on society, illustrating this relationship.

The above arguments will now be assessed as regards their implications for social work with older people, with particular emphasis on the issue of the kind of discrimination experienced by older people in later life.

Ageism and older people

The social construction model has certainly been fruitful in terms of the analysis of ageing at macro-economic and macro-social levels. At the same time, a particular form of oppression identified from the way older age was constructed was identified in the form of ageism. First coined by Robert Butler (1963), the concept increased in popularity with the growth of such social movements as the Grey Panthers in the US (Kuhn, 1977). Ageism is defined, according to Butler (1987, p.22):

> 'As a process of systematic stereotyping and discrimination against people because they are old, just as racism and sexism accomplish this for skin colour and gender...Ageism allows the younger generation to see older people as different from themselves: thus, they suddenly cease to identify with their elders as human beings and thereby reduce their own fear and dread of ageing... At times ageism becomes an expedient method by which society promotes viewpoints about the aged in order to relieve itself from responsibility towards them.'

Biggs (1993) notes that ageism is now established as a starting point for investigations into older age. Although a number of criticisms have been made of this concept (Kogan 1979, Bytheway 1994), it has been valuable in providing connections with the activities of institutions on the one side, and beliefs about old age on the other. Ageism finds institutionalised expression through job discrimination, loss of status, stereotyping and dehumanisation. It focuses on the way in which old age is transformed from a gain and extension of the life course, into an economic and social problem or burden. At the same time, it also opens out the possibility of links with different forms of professional practice with older people. To assess how these might be developed, the next section of this chapter considers the implication of an anti-ageist perspective for social work practitioners.

Developing anti-ageist practice

The development of anti-ageist practice involves addressing a range of important issues that influence, constrain or facilitate good practice. These factors can be seen to apply at four levels: social work practice at the individual level; influencing and shaping the practice of other social workers; influencing policy and agency procedures; and theory development. This section will address each of these in turn, with a view to moving towards an understanding of anti-ageist practice.

Patterns of individual practice

Traditional practice with older people relies heavily on assumptions that, on closer critical scrutiny, reveal themselves to be reflections of ageist ideology. A basic component of anti-ageist practice, therefore, is a willingness to subject our own practice to critical review – a preparedness to reconsider established patterns of practice. Such a review can be addressed in terms of a number of key concepts, namely: empowerment, partnership, and challenging destructive processes such as infantilisation and dehumanisation. We shall consider each of these in turn.

Empowerment refers to the process of helping people increase the degree of control they have over their lives. It involves:

- *challenging stereotypes of dependency.* A focus on empowerment seeks to ensure that older people are not made dependent on workers or services. The concept of 'interdependency' (Phillipson 1989) is a useful one insofar as it acknowledges that older people have not only needs but also positive strengths to offer.
- *giving people choices.* Instead of acting as the 'expert' who has all the answers, a more appropriate approach is one in which we help to identify choices, and support the older person through the process of deciding upon options and carrying them through.
- *focusing on self-esteem.* The negative stereotypes of ageism tend to be internalised by older people. This internalised oppression can then have a detrimental effect on confidence and self-esteem (Thompson 1995). Empowerment can counter the potential negative effects of ageism on self-worth.
- *recognising oppression.* Traditional approaches can be criticised for failing to recognise the significance of oppression. For example, in working with ethnic minorities, a common misunderstanding is that it is better to 'treat everyone the same' (the 'colour-blind' approach). This fails to demonstrate sensitivity to people's ethnic needs, values and patterns, and the experience of racism (Blakemore and Boneham 1993). Similarly, it needs to be recognised that older people constitute an oppressed group as a result of the predominance of ageism. If this point is not acknowledged, practice may reinforce ageist stereotypes.

This last point is particularly significant for, as Ward and Mullender (1993) argue, we need to guard against traditional practice being translated into a new language without fundamental change to how service users are treated: so what does it mean to empower someone? It has become clear that, by itself, the term cannot provide an adequate foundation for practice. The language of empowerment trips too lightly off the tongue and is too easily used merely as a synonym for 'enabling' (Mitchell 1989, p.148). Unless it is accompanied by a commitment to challenging and combatting injustice and oppression, which shows itself in actions as well as words, this professional Newspeak allows anyone to rewrite accounts of their practice without fundamentally changing the way it is experienced by service users.

Partnership, as a practice principle, is closely linked to empowerment insofar as it entails the worker using his or her power, influence and access to resources to work alongside service users in pursuing jointly agreed goals. This involves encouraging older people to play as full and active a part as possible in the process of assessing needs and developing an action plan geared towards meeting them. It is a movement away from a medical model of service delivery in which the problem is 'diagnosed' by the expert and a course of 'treatment' prescribed. The partnership model, by contrast, locates the worker's expertise in facilitating the joint identification of needs to be met, problems to be solved and barriers to be overcome. In this way, worker and service user can collaborate in forging a way forward that has a far higher likelihood of success than an approach involving externally defined needs and an externally imposed means of meeting them.

A skilful approach to partnership can bring many benefits, not least the following:

- a higher degree of participation by the service user that can have a positive effect on confidence and self-esteem – a greater feeling of control over what is happening;
- a broader picture of the circumstances, incorporating the service user's perspective as well as the worker's;
- less resistance to necessary changes as a result of a higher degree of commitment to the joint process.

Smale *et al.* (1993, p.11) draw a distinction between a 'Questioning' approach to assessment and care management and an 'Exchange' approach. The former presents the worker as someone who forms a professional judgement on the basis of asking a number of questions. This process therefore tends to be dominated by the worker's agenda. The latter, by contrast, involves an exchange of information through which needs and potential solutions are jointly explored:

> 'In the Exchange model two or more people come together and arrive at a mutual understanding of the nature of the problem, its solution or management, through the interaction between them. Typically the professional will not lead the content of the dialogue because he or she will not know any more, if as much, as the other people about the situation, its problems, or what existing resources could contribute to the "solution", *i.e.* the potential components of a "package of care". The professional follows or tracks what the other people say and communicate. To lead is to assume that the professional knows where to go, and often this will be straight to a service-led response.'

The Exchange model illustrates working in partnership, and helps to clarify what is involved in replacing unsatisfactory traditional models of practice with an approach premised on anti-ageism.

A further important aspect of anti-ageism is a preparedness to counter destructive processes. We shall focus on two in particular, namely infantilisation and dehumanisation. Infantilisation refers to the tendency to treat older people as if they were children. This involves patronising them, not consulting them and generally disregarding their rights as adult citizens (Thompson 1992). Hockey and James (1993) describe the ways in which metaphors of childhood are used to shape the experience of ageing and, in so doing, contribute to the social construction of dependency. Practitioners therefore need to be very careful to ensure that the language used, attitudes adopted or steps taken do not infantilise. That is, practice needs to be premised on a model of older people as adults with rights, rather than 'second generation' children.

Dehumanisation is a parallel process in which older people are treated as things, objects rather than subjects, and seen as distinct from 'ordinary' people. According to Thompson (1993, p.86).

> 'There is a strong ideological tendency to dismiss older people, to deny them their humanity. We found a good example of this in an article in a newsletter of a local "Alcohol Forum". The author, a psychiatrist, is discussing safe limits for weekly alcohol consump-

> tion when he comments that: "Safety limits are proposed in terms of alcohol units per week (10) but these limits are for males or females, not for the elderly'. Although the good intentions of the author are apparent elsewhere in the article, the common tendency to distinguish between "ordinary people" (that is, males and females) and "the elderly" is clearly in evidence.'

Anti-ageist practice therefore requires a sensitivity to such dehumanising tendencies so that we do not lose sight of the fact that older people are people first and last.

Influencing the practice of others

While a review of our own practice is a necessary condition for developing anti-ageism, it is not a sufficient condition. We also need to consider influencing the practice of others. This is because discrimination and oppression are not isolated incidents of misfortune or bad practice; they are fundamental aspects of the way in which society is organised (Thompson 1993). It is for this reason that we need to develop practice that is anti-discriminatory, rather than simply non-discriminatory. That is, it is not enough to seek to eradicate discrimination from our own practice while condoning it in the practice of others. Practitioners therefore need to develop the skills of:

- recognising examples of ageist practice in the work of colleagues;
- challenging in sensitive and constructive ways;
- promoting an ethos in which anti-ageism is taken seriously and respected;
- being able to deal assertively and constructively with 'counter-challenges'.

Fortunately, although challenging others may be difficult, its impact can be significant. Often, people respond very positively to challenges that are sensitive, constructive and couched in respectful terms, rather than in terms of a personal attack.

Influencing agency policy

The policy level is one that has major implications for practice insofar as it sets the parameters and ethos that underpin practice. There is therefore an important role for practitioners in challenging ageist aspects of policy or procedures, and pressing for the development of an explicitly anti-ageist policy. Admittedly, organisational power structures are likely to be resistant to bottom-up change and, realistically, major changes may not be possible, in the short term at least. However, there is a danger of adopting a defeatist attitude. Acknowledging that change may be difficult, slow and gradual should not be equated with seeing change as a vain hope or impossible dream.

An important strategy is to seek out all possible means of influencing policy. This may be through correspondence (both individually and collectively) with managers, participation in working parties or planning groups, trade union activities and so on. The primary skill is that of being an 'organisational operator' – developing a good understanding of how organisational power structures and channels of influence operate, and recognising opportunities for playing a strategic part in taking them in an anti-ageist direction.

Staff efforts in this regard can, potentially at least, be supplemented by the influence of service users. While working in partnership on a case-by-case basis is an important part of developing anti-ageist practice, the principle can be extended to include the notion of 'participation'. User participation implies being involved at a number of levels, rather than simply planning one's own care. These include planning, monitoring and evaluating services, contributing to policy development, operationalisation and review, and perhaps also contributing to training or even staff recruitment. Where such participation can be encouraged, there is a higher likelihood of ageist policies and practices being identified and challenged.

Developing theory

Traditional theory reflects a medical model of ageing in terms of focusing too narrowly on biological aspects of ageing. However, this is not to say that such theory has no value whatsoever. It is possible for certain aspects of traditional theory to be reworked within an anti-discriminatory framework. We shall give two brief examples to illustrate this point.

Thompson (1991, pp.15–16) presents a case for 'revitalising' traditional crisis theory by amending its basic principles to make them consistent with anti-discriminatory practice:

> '...traditional crisis theory can be criticised for adopting a predominantly white, middle-class male perspective on a range of

> issues which relate very closely to structured inequalities and the oppressive social divisions which stack the odds against certain groups in society. An understanding of social disadvantage and discrimination must be incorporated into the theoretical framework if a new crisis theory is to replace the old and thereby make a contribution to anti-discriminatory practice.'

Similarly, Mullender and Ward (1991) argue the case for 'self-directed groupwork' as an approach to groupwork that incorporates anti-oppressive issues and values, and therefore goes beyond the traditional confines of groupwork theory.

These examples demonstrate that some theories at least can and should be developed to incorporate anti-discriminatory practice and, in so doing, present an important challenge to both theorists and practitioners.

Conclusions

This chapter has provided a brief review of some of the challenges posed by the social construction perspective within gerontology. By way of conclusion, some comments will be made about future issues in the experience of old age. First, over the past five years (and partly through the influence) of critical perspectives, greater attention has been given to the extent of diversity within the older population. For example, Blakemore and Boneham's (1993) *Age, Race and Ethnicity*, is an important review of the reality of ageing in a multi-racial society. It documents the various responses to growing old amongst minority groups, and demonstrates the urgent need for more detailed survey and ethnographic research on this topic. Studies in relation to gender and ageing by Arber and Ginn (1995), and by Bernard and Meade (1993), have also provided valuable perspectives on contrasts between men and women, especially in areas such as the experience of poverty, caring and personal relationships. More generally, however, there is a dearth of studies dealing with social class differences in the experience of growing old. Surveys such as the General Household Survey (OPCS 1996) give a hint of some of the material differences in the lives of Britain's older people (as do comparable surveys). However, there is an urgent need for more detailed studies which show the extent to which growing old is shaped by the cumulative advantages and disadvantages of particular class positions. Such investigation is made especially urgent given the growth of inequalities over the past 10 years, especially amongst the older age groups (Rowntree, 1995).

Second, significant changes are also underway in respect of the self-identity of older people. A major component here is the growth of early retirement or early exit from the workforce. At the beginning of the twentieth century, the majority of people continued to work or to look for work until ill-health set in or they reached the point of exhaustion. At the end of the twentieth century, the majority are leaving paid employment well before this point, with a rapid expansion in the number of years currently spent in the period defined as retirement (Laczko and Phillipson 1991). Old age has been dramatically reconstructed in the absence of full employment. This change – in the context of a post-industrial world – is almost certainly irreversible. It is transforming the lives of all older people; it will also affect those who work with them. The opportunities for professional social work with older people will be substantial, albeit that it will be of a very different nature than that which has characterised the past two decades. This chapter has tried to address some of the questions which a future social work will need to address, especially one which challenges the discrimination and oppression faced by many older people.

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Chapter 6

'I Was Given Options Not Choices'

Involving Older Users and Carers in Assessment and Care Planning

Fiona Myers and Charlotte MacDonald

This chapter explores the reality for service users and their family carers of their involvement in care planning and the extent of the opportunities to exercise choice in how their needs are met.

Central to the rhetoric of community care is the principle of greater user and carer involvement. As articulated in the White Paper *'Caring for People'* (Department of Health 1989), and in subsequent official guidance, the objective is to give users and carers 'a greater individual say in how they live their lives and the services they need to help them to do so' (Department of Health, 1989). Nonetheless, there is what could be called a 'hesitancy' apparent in policy statements. While seeking to redress the balance of power there is, at the same time, a recognition that this shift is not absolute. Unlike consumers of other services, for users and carers, ultimately it is 'the assessing practitioner who is responsible for defining the user's needs' (SSI/SWSG 1991, p.53). Further, the involvement of users and carers in the decision making process is not the same as handing over decision making authority or the resources to act on those decisions.

As a number of commentators have noted, there is a potential contradiction between a policy which seeks to promote consumer choice and participation while also seeking to ration and prioritise resources (Allen, Hogg and Peace 1992, Ellis 1993, Caldock 1994). Lloyd (1991), who analyses this tension in terms of competing 'liberal' and 'conservative' discourses, suggests there is an incompatibility between a 'bottom up' approach emphasising the individual's role in defining their own needs, selecting and controlling the delivery of services and, where necessary, able to seek redress, with a 'top down' approach where 'management' assesses need and allocates scarce and rationed resources.

This tension at the heart of community care policy is not of abstract political or philosophical interest, but makes itself felt at the grassroots level of policy implementation. For frontline workers it can mean, as North (1993) suggests, having to act both as 'neutral advisers' and as 'gatekeepers' to scarce resources. For people seeking support, even if encouraged to participate, the opportunities to act as empowered consumers may be constrained by the limited range of options from which to choose.

Allen *et al.* (1992) found from their study in England, completed immediately prior to the introduction of the new community care procedures, that older people tended to have no choice over what went into their package and that participation was limited to agreeing with what was offered. Given the contradictory nature of the policy, the question this raises is whether, from the accounts of service users and carers, any progress has been made in shifting the balance of power. From interviews undertaken following the implementation of community care, this chapter explores some of the implications of this tension for older service users and informal carers.

The study

The data on which this chapter draws comprise part of a larger Scottish Office funded study being undertaken in four regions in Scotland by the Social Work Research Centre at the University of Stirling. In the course of the study data from a number of different sources are being collected. First, the completion by workers of case monitoring forms for people referred for comprehensive assessment, both at the time of assessment and after a period of nine months (or on case closure), provides information on the social circumstances, identified needs and services provided to 247 people, of whom 144 (58%) are aged over 65 years. Second, interviews with 65 social work department practitioners explored their perspective on the introduction of community care policies and procedures (MacDonald and Myers 1995). Third, users and carers identified through the case monitoring forms, were interviewed about the assessment and care planning process. Follow-up interviews are currently in progress aiming to explore their experience of the implementation of care packages.

The main focus of this chapter will be the responses of the older users and their informal carers, but to set the context it may be useful just to briefly sketch a picture of the practitioners.

The practitioners

Although all the workers in the sample were employed by Social Work Departments, they did not all come from a social work background. Included in the sample were people from nursing, occupational therapy and home care backgrounds, as well as one health visitor and one community alarm organiser. A number of the practitioners had specialist expertise in working with older people. In one region, for example, one worker had been an elderly specialist social worker, another had been a social worker attached to a social work team for older people. But these were in some respects atypical. The majority had previously worked as generic workers, or as specialists in learning disabilities or child care. As a result they were not necessarily experienced in the needs of older people. With the exception of concerns around recognising dementia and the legal implications, this lack of experience was not, however, reflected in their demands for further training.

In terms of their attitudes toward involving users and carers in the process, the majority of practitioners expressed support for greater consumer participation. However, what also became apparent from their comments were the obstacles to realising this goal. Some of these stemmed from the structural constraints within which workers were having to operate, in particular the pre-determined eligibility criteria and the limited options from which to offer people choices. Aspects of practice could also, unwittingly, serve to undermine the involvement of users and carers. For example, workers differed among themselves as to the degree to which they let users and carers see, sign and retain copies of assessment of needs forms and care plans. Third, workers suggested barriers which stemmed from the users and carers themselves, not just communication difficulties, but also difficulties of comprehension on the part of a confused user or someone with dementia. Additionally, workers perceived what they felt was a reluctance on the part of some users to take up the mantle of the informed consumer. Older people in particular were felt to be particularly uncomfortable with the proffered gift of participation. One worker commented,

> 'For a lot of the older people, part of their need is for someone to do it for them, and not to have the hassle of finding a place for respite or phoning round for care services.'

Other studies suggest that this reliance may be due not to age *per se*, but to the sense of powerlessness on the part of users and carers, and a desire for a knowledgeable and assertive advocate to act on their behalf (Robertson 1993). Meethan and Thomson (1993) also found a tendency for users and carers not only to defer, but to seek to hand over power. This apparent handing over of power may be a positive choice in the way that a 'client' would employ a lawyer or other technical specialist to act as broker, but it may also be an acknowledgement of the asymmetrical power relationships within the welfare market. Workers not only have the knowledge of the market, and the skills to circumnavigate its complexities, but are also keyholders in their own right. As such, users and carers, although encouraged to be partners, may not experience it as a partnership founded on equality.

Users and carers

The users and carers were identified from the case monitoring forms. Workers were asked to approach all the people included in the main study to ask if they were willing to be interviewed. Inevitably with this approach workers will tend to sift out people who they feel would be unable to participate, perhaps because of a communication problem or dementia. People with whom the worker had no further contact or those with whom the worker had a difficult relationship might also be excluded. Identifying an appropriate informal carer may also not be without its problems, as was found in relation to one younger client where the identified 'carer' proved not to be the person caring for the client in the sense of providing physical and personal care. This loss of control over the selection process was, though, balanced by the preservation of the privacy and confidentiality of those users and carers who did not wish to be approached.

A total of 52 users were interviewed, 31 (60%) of whom were aged over 65 years. Of these, over three-quarters were women. Interviews were undertaken with 36 informal carers, 19 of whom were supporting someone aged over 65 years.

Among the carers of older people, four were male and 13 female, the remaining two 'carers' were in fact married couples. In three cases the carer was the husband of the service user, one was the son and one was a sister. The largest group were daughters caring for a parent, comprising 12 of the sample of carers of older people.

In 10 cases the carer only was interviewed because the older person was felt to be unable to participate. In 21 cases the user only was interviewed, and in 9 cases both user and carer were interviewed. Where carers were interviewed it was to obtain their views as carers, not as proxies speaking on behalf of the user.

Where an interview took place with a user and/or a carer, three quarters of the older service users were living in the community, the remainder were in residential care.

Involving users and carers

Terms like 'involvement', 'participation', 'choice' can mean different things to different people. A worker's idea of involving a user may, from the user's point of view, amount to being informed of a decision made elsewhere. In order to conceptualise 'involvement' a number of commentators have drawn the analogy of a ladder (Arnstein 1969, Taylor *et al.* 1992). Although the descriptions of the different intermediary steps on the 'ladder' may vary, essentially they describe the same process of movement from a low level of participation in which decisions are imposed on an individual with little or no discussion of whether, how, where and when support will be made available, through to a high point of service user autonomy in decision-making and resource allocation.

In the context of assessment and care planning, what is at issue is the degree of power or control the user and carer have over the process and its outcomes. Focusing specifically on access to assessment, information sharing and decision making, the aim here is to begin to explore the degree of control and autonomy this sample of older service users and their informal carers appear to be able to exercise over the process. The findings, at this intermediate stage of the project can only be tentative rather than conclusive: raising questions rather than providing answers.

Getting into the system

Not all the service users specifically sought help themselves, or knew who had made the referral. Of the 31 service users interviewed only two had referred themselves to the social work department. Of the remainder, fourteen were unsure who had initially made the referral on their behalf. Carers, on the other hand, appeared to be more proactive with eight of the 19 referring themselves and only two not being aware of the source of the referral.

What is perhaps more important is their understanding of *why* the worker contacted them. Among the sample of users most saw the worker's role in terms of seeing what help they needed. Many identified a change in their own circumstances as triggering the worker's involvement: a substantial number of the users had had falls which had landed them in hospital. But other users cited a gradual deterioration in their ability to cope, or a change in their home circumstances. In several cases these older users were themselves 'carers', and as a result of their own ill-health were less able to provide care. There were also users who recognised that the reasons for the worker's involvement stemmed from their informal carer's inability to continue caring. One, for example, described how the worker came to see her about her going into a home because:

> 'My daughter did not want me in her home...she works most days...(she's) unable to cope with me and her family problems.'

Finally, there were among the service users a few who remained bemused about the worker's involvement. For example, one user who was in a long stay hospital at the time of the interview could not recall the worker being involved at all, and denied that she needed any help. Another service user was unsure who had involved the worker and the reason for the visit:

> 'I was alright, don't know why she came. I think it was just for a chat.'

The carer in this instance referred to her mother's gradual deterioration and the fact that 'you had to go through social work before there would be any placements for care'.

As this example suggests, some carers had very specific ideas as to why a worker became involved, referring to what they perceived as the user's need for residential or nursing home care. Others cited specific types of help they felt they required to assist them to carry on caring. One carer, for example, who made the referral herself, was looking for respite from caring from a demanding parent. Another needed care to be provided while she went into hospital to have an operation. In a number of cases the request for assistance amounted almost to a *cri de coeur*, where a carer felt they could no longer cope with caring.

A recent study describes how much fear can be a motivating force for users and carers (Department of Health 1994), while Meethan and Thomson (1993) describe the relief felt by users and carers on entering into the Scarcroft project. What perhaps should not be overlooked is the possibility that a process which is often set in train at a point of crisis, or when a user or carer is feeling at the end of their tether, or 'like a useless article', may in itself undermine people's sense of their own autonomy, or control over their own destiny.

Exchanging information

Given that users and carers are often, as the seekers of assistance, placed in a dependent position, the onus is much more on the worker to redress this imbalance, both through listening and responding to users' and carers' expressed needs and by providing information.

In Allen *et al.*'s study (1992), just over one half of the older people felt they had had enough discussion about what support and services would be most helpful to them. In the current study users, in general, felt that the worker was listening to them and gave them as much time as they needed, as one remarked:

> 'He let me know he had plenty of time to listen...he was very easy to talk to...I think I discussed all my needs and fears...he's a good listener.'

It could be argued that the apparently high level of satisfaction with workers as people willing to spend time and listen, reflects what Wilson (1993) describes as the public account or socially accepted version, which may be at odds with the private account. However, the responses were not just what Wilson would perhaps describe as 'neutral' polite statements such as 'he's very nice', but quite fulsome praise. One user, for example, described the worker as:

> 'Very kind and helpful, I call her a friend...she has been a brilliant help to me...I think very highly of her.'

Among the respondents, critical comments tended to come not from users but from carers, and tended to be cases where the carer was seeking residential or nursing home care. In several cases, they felt that the worker had listened to them and been prepared to spend time with them, but appeared to be slow to get things moving. In other instances the carers felt the workers involved were too slow to understand the pressure that they, as carers, were under. A number of carers felt constrained from expressing their concerns because the service user was present when the worker came to do the assessment.

What this illustrates is the potential tension between users and carers, and their conflicting perceptions of whose needs the worker should be addressing. This emerged most poignantly in one case where the user wanted to stay living with her daughter but the daughter was seeking a residential placement for her mother. In this case the user felt the worker understood the situation between her and her daughter, but nonetheless 'tried to get me to go to a home. I do not want to go there'. The daughter, for her part, felt that the worker 'would have liked my mother to stay here and have...some day care'. In instances such as these, the worker's role may be that of an arbitrator seeking a compromise solution, rather than the desired solution of either party.

Although the users interviewed indicated that they felt that the worker listened to what they had to say, the comments of the workers suggest that not all users were given a voice. This was found in relation to people with dementia who, although able to express an opinion, were not felt able to make an informed judgement. One worker remarked:

> 'With dementia they don't know what they want and they don't know what's best for them.'

In cases such as these the voice of the carer may not only serve to speak for the user, but also be the loudest in the decision-making process. This is despite, as some workers recognised, the possibility that carers have their own 'agendas'. For users without informal carers the decision-making responsibility may rest solely with the professional. As Fisher (1990) comments, for people deemed unable to make reasoned decisions, 'concepts of choice and participation are nearly meaningless'.

The other side of the coin to being listened to is being informed. Allen *et al.* (1992) found that substantial numbers of both users and carers felt ill-informed about the range of services available. Workers in the current study certainly recognised the importance of enabling people to make *informed* choices. Nonetheless, the comments of the users and carers interviewed suggests that there is a fine line between being 'informed' and being told. In other words, the redistribution of knowledge which would enable the user and/or carer to make these informed choices, may only be partial. One carer, for example, remarked:

> 'I was given options, not choices. I was told what was available,'

while a user explained:

> 'She told me what I was going to get and I told her what I didn't want.'

Given that knowledge is power, this dependence on the worker can mean that at the point of decision making users and carers are again unequal partners in the negotiation process.

Decision making

Users and carers may feel that they are listened to, but when it comes to having what they say acted upon where does the decision making power lie? Which voice carries the greatest weight and what are the decisions to be made?

The responses suggest that the degree of influence over decisions, if not the power to make them, may be unevenly distributed between users, carers and others. In some cases a medical decision to admit someone to hospital effectively removes the choice of social care options (at least in the short term). Second, as suggested above, there were instances cited by the workers interviewed where the expressed views of the user might be overridden because they were not believed to be based on an informed judgement. In cases where a user continued to prove 'recalcitrant', several workers suggested they might consider invoking the law to ensure compliance. Third, there were cases, evident among the sample of users interviewed, where residential care was being proposed but the users themselves felt the decision was effectively out of their hands. One user, for example, felt that she had no choice:

> 'The doctor in the hospital told me I would not manage at home so I had no choice other than to come into this home.'

Fourth, in cases where user and carer disagree, the importance, to a worker, of supporting the carer to continue in their caring role may shift the balance of power toward the carer's preferences, particularly where there is a potential or actual threat of withdrawal of care.

Certainly, several users interviewed felt under pressure to accept residential care because of their informal carer's needs. The comments of some of the carers, however, suggest that they did not always feel that they had any influence. One carer who expected the worker would be instrumental in arranging for her mother to be admitted to residential care appeared resigned to her mother's resistance:

> 'As my mother is not that far gone it is up to her to make her own choice as to what she wants. I agreed. In the end it is nothing to do with me.'

Fifth, of course, is the influence of the worker themselves. Workers are not only advocates and advisers, but also gatekeepers to resources. If a user's or carer's expressed need does not meet local eligibility criteria or agree with the professional's assessment, then professional definitions may prevail. For example, one user interviewed described how he had wanted to move to sheltered housing, but 'the social worker said I was better off where I was'.

Different participants to the process may, therefore, have different degrees of influence over the outcome. But what of the decisions themselves? Users and carers may feel they are a given a good hearing by the worker, but while receptivity to users' and carers' accounts is a necessary pre-condition to consumer involvement, it is not sufficient of itself. Arguably, the touchstone of 'involvement' is the scope which users and carers have to make choices in terms of the needs to be met and the means for meeting those needs. Allen *et al.* (1992) concluded that most of the users and carers in their study had no choices either about what, if anything, went into their package, or about who provided this service and in what way. In so far as consumer choice was exercised it was through refusal or by choosing to discontinue a service. The scarcity of resources was seen by workers, users and carers as putting limits on user/carer decision making powers. Allen *et al.* concluded that 'positive choice among consumers was not really encouraged, and in some cases, was treated as undesirable'.

From the current study, too, it became apparent that, at the point of service provision, for users and carers there can be a number of different levels of decision-making power:

- no opportunity to choose: users and carers are advised what they can have, with only the negative power of refusal (if deemed able to give informed consent);

- opportunity to choose from a limited range of available or pre-determined options;
- opportunity to develop their own package, with the worker acting as broker, or user and carer having delegated authority to make decisions and access to resources.

Levels one and two seem to characterise the experiences of the users and carers interviewed in our study.

Where the decision is between a residential or non-residential care plan, this may ultimately be made by the professional gatekeepers who determine eligibility. One carer, for example, described how the final decision on residential care was 'dependent on a panel vote'.

Among those who had leapt this hurdle, it was clear that even where users were emphatic that they alone had made the decision, it was not necessarily a choice between alternatives. This was either because no alternative was offered, or because of the perceived shortcomings of the only alternatives believed to be available. One service user illustrated this very clearly:

> 'The choice was mine. I chose the home in preference to having the upset of home helps changing…I didn't like the disruption caused when they were changed…sometimes they would be allocated half my usual time. What can they do in half an hour?'

Users and carers did, however, refer to having a choice of homes. But even this could turn out to be more apparent than real, dependent on the availability of places. One user, for example, described how she had been waiting for a place in one home but:

> 'It was made clear to me I would not get a room within (this) home, and I felt I just had to accept this because there was nothing anyone could do.'

Another constraint on 'choice' may be the costs involved both for the users and for the local authority. These interviews with users and carers did not explore charging or their attitudes towards paying for services. These issues are being explored in the follow-up interviews. Workers, however, expressed their concern that people would refuse a service on the basis of cost not lack of need. Thomas (1994) gives some substance to this anxiety in her review of charging policies. But it is not just the cost to the client which may impede choice. Workers were aware that the options available to people being funded by the local authority were constrained by the costs of different resources. One practitioner, referring to residential placements, commented:

> 'The family can look around at the homes. They still have the right of choice provided they are within the financial limits we give them.'

In respect of domiciliary care, too, users and carers would not necessarily experience the process as one of 'choosing', as one remarked:

> 'I didn't choose, you got what was available.'

For some there was some scope for trying out different things, albeit from a limited range. For example, one service user tried meals-on-wheels but did not enjoy the food. The arrangement was changed to a home help coming in daily to prepare and cook meals. Overall, however, the notion that users and carers can pick and choose is undermined by the experience of one carer given the names of five homes for respite care:

> 'Some were far too expensive, some had stopped taking respite, and some were fully booked up.'

There was also little evidence to suggest that users and carers felt able to determine the timing and extent of the service. One service user, for example, remarked:

> 'It would be nice if I could have a longer time of home help. I cannot stretch or bend. The home helps have the inclination, but not the time.'

Nor did their accounts suggest they had much influence over the way the service was provided. One service user was happy to have a home help every day, but would have preferred to have a regular person who would 'know your routine and you would know them'. Another for whom, after some delay, a social carer service became available, commented:

> 'I didn't feel entitled to ask for a type of person who had the same interests as myself.'

The picture which emerges from the comments is of a process whereby the service users and carers agree with what is offered from a fairly standard list of home help, daycare, respite and residential care. As summarised by one service user:

> 'It was decided I would get an extra eight hours home help, I was agreeable to this.'

In general, the respondents did not appear to be encouraged to explore different ways of meeting their needs, nor of being given much scope to choose between means. Their experiences would seem to echo those described by Meethan and Thomson (1993), as decision making between *given* services, rather than greater choice between *possible* services.

While carers seeking residential care for the person they cared for appeared to be more active in asking for what they wanted, on the whole both users and carers appeared to be at a disadvantage in knowing what was available, or possible, or what they were entitled to. As such they were inevitably dependent upon the worker. Furthermore, expectations were limited. Only one user interviewed questioned the level of service she was receiving. Referring to the one and half hour's home help she received each week she remarked, 'But I would have thought I was entitled to more'.

Conclusions

In the context of the assessment, the responses of the users and carers interviewed suggest that they felt they were given a chance by the worker to express their needs, and were listened to. In responding to these expressed needs, however, the comments of the workers as well as of the users and carers imply that different voices carry different weights. The loudest voice may prove to be that of the other professionals and agencies determining need and eligibility.

What also emerges from the responses is the degree of dependence of users and carers on the assessing professional: for support at a time of crisis, for information and for access to resources. It has been argued that for older service users, the ceding of power to a professional may itself be a positive choice. Stevenson and Parsloe (1993), for example, suggest that the concept of 'empowerment' needs to be specifically related to the different material needs of very elderly people, and may need to encompass the older person seeking to hand over tasks which worry them. Along similar lines, Robertson (1993) found that, in recognition of their own powerlessness, older people sought a care manager:

> 'Who had status, who was able to cope with bureaucracy, had good contacts, was shrewd and assertive (with service providers) and could generally ensure the prompt and consistent delivery of the required care.' (p.16)

This approach does pre-suppose that the workers themselves are unfettered by competing demands, but as has been demonstrated (see, for example, Ellis 1993) workers are not only advocates but allocators of scarce resources, using the assessment as a means for rationing demand. In effect, workers too may bring with them other 'agendas'.

As a result of the tension between the competing imperatives of consumer empowerment and management control, people may feel they are listened to and consulted, but, that at the point of decision making, find that the exercise of power is severely constrained. For older service users and the people who support them, there may still be a long way to go on the ladder of participation.

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