Chapter 3

Enabling Older People to Live in their Own Homes

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1. INTRODUCTION

Separating ends and means

Caring for people, as one of its architects has pointed out, was a highly principled, value-led document; it made 'helping disabled people to retain or regain control of their lives a matter of public policy. Its broad objectives have a strong ethical content: people are to be enabled to lead 'as normal a life as possible', helped to achieve 'maximum possible independence', and 'their full potential' and have 'a greater individual say in how they live their lives' (Utting 1996). Much of the Policy Guidance which followed the passing of the NHS and Community Care Act 1990 echoed those same values.

The objectives of *Caring for People*, of which the above is the first, attempted to spell out the means by which those values were to be put into practice.

However this first objective is a complex one and it is unlikely that we would put it in the same form today. It both identifies the desired outcome – that 'people should be able to live in their own homes wherever feasible and desirable' – and makes the further assumption that the way this will be brought about is through the development of domiciliary, day and respite services. It thus mixes ends with means, the outcome with the expected way of getting there.

In order to assess the extent to which the objective has been achieved and whether it still holds good for the future, these two aspects – the ends and the means – need to considered separately. We cannot presume that the development of services as envisaged will have – or would have had – the intended outcome.

Measuring outcomes

Outcomes are not easy to measure. Until 1995, the focus of social services monitoring and research was very strongly on the activities of service agencies, rather than on 'outcomes for people', the effect of services on the lives of

individuals (Nocon, Qureshi and Thornton 1997). 'Success' was being measured narrowly, in terms of service change and outputs – measures of productivity – rather than in terms of outcomes – measures of effectiveness (Harding in O'Neil and Statham 1998).

This has been a source of frustration to service users and carers. User and carer groups express strong feelings about the need to gather credible evidence about the effectiveness of services:

> '*Some respondents stated that the monitoring and evaluation of service impacts was central to the planning and development of needs-led services. Such monitoring would indicate whether services were meeting users' and carers' needs, whether they were of a sufficiently high quality, and what changes needed to be made'.* Failure to meet needs appropriately *'not only causes distress, but also represents a waste of money'.*
> (Nocon, Qureshi and Thornton 1997).

Younger disabled people and other groups of service users and carers have led the way in insisting on defining their own desired outcomes – and Direct Payments have been one of the consequences of that.

It has taken longer for older people to become similarly influential and is only now beginning to happen. There are increasing numbers of initiatives which enable older people to voice their own objectives and to influence the planning and service development of local agencies (Scott 1998, Dunning 1998, Trowbridge 1998). Nationally, over the last two years, such initiatives as the user-led Shaping our Lives project based at the National Institute for Social Work and the programme of work on the outcomes of social care at the Social Policy Research Unit at the University of York (both funded by the Department of Health) have also begun to change the paradigm.

In the meantime, much of the assessment of the effectiveness or otherwise of the community care changes – of the impact of such policies on the lives of ordinary people – must depend on the valuable but inevitably patchy anecdotal evidence of service users and carers themselves and of advocacy organisations, and on those still rare pieces of research which take the experience of older people themselves as their starting point. There is as yet no more systematic monitoring of outcomes on which to base an assessment of the effectiveness of community care policies in meeting people's needs.

2. HAS THERE BEEN AN EXPANSION OF DOMICILIARY, DAY AND RESPITE CARE? AND HAVE FRAIL OLDER PEOPLE BEEN ENABLED TO REMAIN IN THEIR OWN HOMES AS A RESULT? IS PROGRESS TOWARDS THESE ENDS CONTINUING?

The verdict is very mixed.

Between 1993 and 1997, there was a 13% reduction in the number of older households receiving home care. The numbers dropped by 60,000, to 403,200 households. Those affected by this reduction were mostly between 65 and 85 – there was a slight rise in the numbers of people over 85 receiving the service.

However, the average number of hours of home care provided to each household rose by 60%, from 3.5 hours a week in 1993 to 5.6 hours in 1997.

Over the same period there was an increase of 25% (from 123,100 to 153,700) in the number of attendances at day centres by people over 65 (DoH 1995, 1998). For those with carers, respite care services can help to sustain the caring relationship and thus enable frail older people to remain at home – indeed respite services are given a very high priority by carers themselves. There are no national figures with regard to the availability of respite care – we do not know whether it has increased or not.

So fewer people are getting domiciliary care but those that are are older and are getting more hours of help. Those who meet the now very high eligibility criteria for access to services of most local authorities are those who quite literally could not manage some of the most basic personal care tasks on their own. Had more intensive domiciliary help not been available, they probably would not have been able to remain at home. So some older people with high and complex care needs have probably been enabled to remain at home who might otherwise not have done so.

However, this is only part of the picture. Three other sets of pressures may well have had the opposite effect and resulted in a premature loss of independence for many older people.

Low cost ceilings

Many local authorities have low cost ceilings on the provision of home-based care to older people (day, domiciliary and respite care), usually equal to the net cost to the authority of a residential home place once pensions and entitlements are taken into account. Residential care costs for older people are themselves held at low levels (usually considerably lower than comparable places for younger people (Laing and Buisson 1998)), and there is often little flexibility in these limits to allow for particularly high levels of need or particularly difficult circumstances. The cost ceiling for domiciliary care is thus very restricting and it is highly likely that many older people who would have preferred to remain at home have not had that option, because a sufficient level of support could not be provided within those limits.

From hospital to care home

A further difficulty has arisen as a result of the withdrawal of the NHS from much continuing care for older people, together with the speed-up of hospital 'throughput'. With little help or time to regain health and mobility following a period in hospital, and huge pressures on hospital beds, many older people have been discharged straight from hospital to nursing or residential homes; in some local authority areas, the great majority of new admissions to care homes are older people who come through this route. Once there, many have stayed.

> *In this most basic respect, Care in the Community has failed older people – it was intended to be about supporting older people at home rather than in long term NHS care. Instead the enormous growth in private nursing homes has simply meant the replacement of one form of institutional care by another – one that older people would not choose given a viable alternative, and one that has cost implications for the individual.*
> (Strathclyde Elderly Forum 1998)

This assertion is borne out by the Audit Commission which reports a 38% reduction in the number of NHS beds designated for older people and an almost ninefold increase in nursing home beds over a period of thirteen years to 1996 (Audit Commission 1997). As the Commission points out, one of the legacies of the 1980s (and one which has powerfully affected the implementation of the *Caring for People* White Paper in the 1990s) is '*the change to the cut-off point at which the NHS stops providing care*'.

> '*Placed centrally between the NHS and independent sectors, social services encounter difficulties at both these interfaces.*' These are '*the key pressure points within the system.*'

The Department of Health, through its 1997 initiative, 'Better services for vulnerable people', has sought to encourage health and social services authorities to work together to improve recuperation and rehabilitation facilities, in order to ensure that older people are restored to maximum health and mobility and to prevent unnecessary dependency. But the absence of such services over the last ten years has meant that many older people who might have returned to their own homes never did so, and that social services (and personal) resources that might have improved support to older people at home were instead diverted to meet residential care costs.

Loss of domestic help and other forms of 'low level' support

Furthermore, many older people who have needed a lesser level of support to retain their independence have had to make private arrangements or do without help, since few local authorities now provide what is seen as 'low level' help.

Older people greatly value 'that bit of help' that enables them to retain their independence.

> '*You just don't think of yourself as old and it's only when you come up against something that you can't do, I can't get on steps now to get up to the shelf, that you realise.*'
> (Clark, Dyer and Horwood 1998).

Clark *et al.* point out that the distinction between personal care and domestic help '*does not withstand close scrutiny*'. They highlight the irony that only those who 'qualify' for personal care are eligible for domestic help, yet the tasks of personal care eat up the time allotted.

For older people, however, increasing difficulties in maintaining their homes causes real distress and loss of confidence. The difficulties that are frequently raised by older people themselves include lack of help to undertake small maintenance jobs, like changing lightbulbs or fixing dripping taps; lack of help with regular household chores, like cleaning and washing curtains; and lack of transport to enable them to keep in touch with friends and valued activities, do their own shopping or visit the doctor.

> '*I want to stay in my own home but what I need are services I can depend on and that work together and talk to each other. Other than by illness, I feel it would be the worry of carrying out maintenance, cleaning and gardening of my home that would drive me into moving into sheltered housing or a home.*'
> (quoted in Frazer 1996)

Older women in particular feel so strongly about the lack of help with housework that many pay privately for help, regardless of their income.

> *'Their ability to manage the physical environment and be seen to do so impacts on their well-being and sense of self as a competent adult member of the community. These are crucial factors in the maintenance of health, function and the ability to adapt to the cumulative losses that ageing can involve and relatedly in social inclusion.'*
> (Clark, Dyer and Horwood 1998)

The lack of this whole tranche of services – some of which were always in short supply but some of which have actually been lost over the years since the *Caring for People* White Paper – is probably contributing to an erosion of independence amongst those for whom 'that bit of help' would make all the difference.

Quality of care

Equally importantly, we have little hard evidence to say whether or not those who do remain at home are getting enough care or the right mix and quality of care. It may be that older people are being helped to remain at home, but with a poor quality of life.

Concerns about quality arise on a number of fronts. At the most basic level, service users and carers complain about a lack of reliability, consistency of staffing and choice in who provides the care and what they do. (Clark, Dyer and Horwood 1998, Harding and Beresford 1996). Never to be sure that someone will turn up, or that the person expected will appear, and to have no choice or control over who comes into your home to provide the most intimate personal care – to have to put up with people you don't like, or who are rough or bad-tempered or careless – imposes great strains and anxiety on the person who is reliant on that service. Service users are quite clear that *how* a service is delivered is as important to them as *that* a service is delivered.

> *Too many home care staff, especially among young people, lack even the most basic domestic skills and are not fit to respond to medical emergencies or care for very frail people.*
> (National Pensioners' Convention in Harding and Beresford 1996)

> *So often it is the style or the way services are delivered rather than the service itself which produces a quality service. This makes it quite difficult to separate out quality of services from quality of relationships; the home carer who gets you up in the morning can do this in an empowering way which enables you to face the effort of the day positively or in a way which leaves you dressed and ready but not psychologically ready. Beyond the basic skills, this empowering experience comes from the quality of relationships. Unfortunately most people's experience of using social services means it is easier to say what does not make an empowering experience than what does.*
> (Wiltshire Users' Network, *ibid*)

Secondly, it is constantly frustrating to service users that care workers are only permitted to undertake a prescribed range of tasks, irrespective of their own priorities. As a group of older people recently emphasised, '*independence means different things to different people*' (JRF 1998), and what is needed to sustain independence with peace of mind varies similarly. Living to someone else's

timetable and being unable to get done tasks which worry you and prey on your mind – having to accept very limited horizons and standards that distress you – is not conducive to quality of life.

The tasks that home care workers undertake tend to focus almost exclusively on the direct personal help needed for the basic activities of daily living – washing, eating, dressing, using the toilet etc – and may also include tasks that verge on nursing, such as skin care and catheters. There is little time or money left for anything beyond these functional survival needs. Wider activities and those personal priorities and aspirations that would enhance quality of life are precluded. This very restricted view of what constitutes acceptable domiciliary care is a long way from the 'flexible needs-led service' envisaged in the early idealistic days of care management following the publication of the *Caring for People* White Paper.

Conclusion

The conclusion must be that, while there has undoubtedly been an increase in personal care to some older people, there are grave doubts about the quality of life that has resulted from this. Meanwhile, many older people have ended up in residential or nursing home care due to low cost ceilings on the provision of domiciliary care and the lack of rehabilitation facilities and intensive short-term support to enable them to return home from hospital. In parallel, less intensive forms of home-based care, which may well have been sustaining the independence of many thousands of older people, have been lost, with unknown and unexplored consequences for increased dependency.

3. HOW MIGHT THE OBJECTIVES HAVE BEEN PUT INTO PRACTICE MORE EFFECTIVELY? WHAT ARE THE KEY REASONS FOR THEIR SUCCESS OR FAILURE? AND HOW MIGHT FUTURE SUCCESS BE ASSURED?

Getting beyond maintenance and safety

While the nature and objectives of social services for younger people have begun to change markedly over the last few years, reflecting a growing awareness by professionals and their agencies of the need for services which promote autonomy and inclusion in mainstream life and activities, the same is much less true with regard to services for older people.

By and large, social services for older people are still perceived by service agencies as being overwhelmingly about maintenance and safety.

> '*The evidence from Social Work in Partnership is that older users are often in the position not only of having their needs defined for them but of having to accept forms of intervention. The mandate for such work rarely derives from the legitimate framework of the Mental Health Act 1993 or the National Assistance Act 1948, but is more often than not a form of illicit coercion, satisfying wider society's needs to ensure the safety of older people but contravening the needs of older people themselves to define their problems and to control actions taken on their behalf.*'

(Marsh and Fisher, quoted in Morris 1994)

'Whilst day services for people with learning disabilities, mental health problems, physical and sensory impairments have begun to feel their way towards an inclusive model, I have found almost zero awareness in services for older people . . .'
(Bates 1998)

The first quotation above stems from work carried out in the late 1980s and early 1990s, the second from current work. In strong contrast to the major shifts in thinking and changing practice in social work with and services for other adults, the culture of services designed for older people has, with some very honourable exceptions, barely changed over the last ten years. Indeed it may well have become less inclusive and more segregated (and hence more stigmatising) as the range of people who 'qualify' has narrowed.

The reasons why this has happened are probably many and various.

They undoubtedly include the financial pressures local authorities have been under, responding to the need to get older people out of hospital beds, and to make limited resources stretch as far as possible. Together with the injunction to target resources at 'those in greatest need', this has led to a narrowing of the definitions of social care for older people and a reduction in the range of services available.

Secondly, older people have rarely themselves been heard in discussions about priorities and service development. They have not had a way of voicing their own priorities or discussing how best to meet them. This is only now beginning gradually to change and has yet to make a significant impact on the nature and form of services.

Thirdly, administrative systems operate in ways which exclude people on the basis of age alone, making the creative use of public resources and personal entitlements more difficult to achieve. Older people are not, for example, eligible for Direct Payments, Independent Living Fund payments, the mobility component of the Disability Living Allowance, higher and more flexible ceilings to the cost of community care packages and so on (though they are eligible for the 'residential allowance' when in residential care).

And fourthly, work with and services for older people remain low grade and low status activities, reflecting the status of older people themselves in our society. All too often such work does not attract the energy and attention needed to stimulate real change.

Aspirations and outcomes

For the first objective of the *Caring for People* White Paper and its underlying values to be realised, services for older people need to join services for other adults in the mainstream of change.

There are few real differences between the aspirations of older people and those of younger disabled adults – though the language used to express those aspirations is sometimes different. They share with younger people the aspirations of retaining independence and autonomy, of being in control of one's life, of having choices about how one lives one's life and having one's own priorities respected (Harding 1997).

The message from older people themselves (and from those in middle age) is clear when they are given the opportunity to voice it.

> 'There was a clear consensus that if they were to be able to maintain their independence and keep control of their lives, there would be certain pre-requisites: in particular financial security; appropriate and timely information; and help to maintain a healthy body and mind.'
> (Henwood and Waddington 1998)

> 'Being able to live independently and to exert control over their lives requires services to be provided to older people in ways that are consistent with their needs and preferences, and in a style which promotes their independence rather than encouraging inappropriate dependency.'
> (Henwood and Waddington 1998)

> 'Users should be able to choose from a range of services which ones best meet their needs. We need genuine user-led provision, not simply the continuation of services defined as appropriate by professionals.'
> (Strathclyde Elderly Forum 1998)

It is important to stress that these aspirations are common to *all* older people, not just those who are relatively active and healthy. There seems to be a common misapprehension amongst policy makers and providers of services that there are two categories of older people: those who need 'care' and those who do not. However the evidence from older people themselves is that inclusion and quality of life are just as important to those whose health or mobility are impaired as it is to more active older people. Ill-health and disability may make it more difficult to achieve quality of life, but they do not change its definition: they simply present additional barriers that have to be taken into account and overcome in order to achieve it.

In order to begin to achieve those aspirations (which are entirely in sympathy with the aims of the *Caring for People* White Paper) and the objective of independence in one's own home, it is necessary to rethink fundamentally the ways in which that objective could be met.

A broader strategy

A wide range of public and private facilities and services affect the capacity of older people to live in their own homes and remain independent – much wider than the domiciliary, day and respite services identified in *Caring for People*, or than health and social care alone. Income level, accessible and affordable transport, comfortable housing, safe and accessible environments, access to adult education, libraries, cultural and sports facilities and so on are all significant factors which either enhance or undermine independence and inclusion.

> 'The needs of older people have to be considered in the round. Remaining healthy, active and independent depends on a complex of factors, all of which need to be in place for each to be effective . . . Good warm comfortable housing is important, but inadequate without access to good quality care and support. Access to primary health care is crucial, but not sufficient if people are immobilised and cut off from friends and activities by poor or non-existent transport.'
> (Harding 1997)

One initiative to listen to and act on the priorities of local older people in a rural area of Wiltshire, concluded that

'older people and carers (like the rest of us) see their own lives as an interconnected whole, not separated into health, social and other categories, and local care planning would have to address this wholeness and, over and above meeting people's essential care needs, respect the priorities that older people set for achieving "quality of life".'
(Frazer 1996)

There is a growing recognition that a more holistic approach is needed. An ageing population requires *'new strategies not just more services; new imaginative initiatives, not just more of the same'* (Benington quoted in Harding 1997).

One of the Health Action Zones announced by Frank Dobson in April 1998 takes just this holistic approach:

'In Tyne and Wear there will be a new partnership approach towards improving the health of elderly people including a new system for assessing high risk, improved access to public transport, improved special housing provision and a programme to improve home insulation and reduce hypothermia.'
(Laing and Buisson 1998b)

Some of the pilot areas identified in the 'Better Government for Older People' initiative take a similarly broad approach. But these are still rare examples.

Unless public policy recognises that older people are affected by the full range of public policy initiatives, the independence of older people will continue to be defeated by sheer lack of access to the ordinary things that make up daily life.

The nature of social services

The provision of domiciliary, day and respite care is certainly one aspect of the necessary support. But the nature, quality and range of those services need to be reassessed to ensure that they actively promote and put into practice the principles of autonomy and inclusion and reflect the aspirations that are so important to older people themselves.

'When older people do become in need of support, it is important to look firstly at the kind of care and support that should be provided, rather than concentrating on how to pay for existing models of services.'
(Strathclyde Elderly Forum 1998)

Much greater choice and control needs to be put into the hands of those who need personal care: choice about who provides them with support and about what they do. The key to a good quality service, according to those on the receiving end, is the relationship between the person using the service and the person providing it – along with reliability, continuity, cultural appropriateness, flexibility and basic skills and knowledge (Harding and Beresford 1996). Direct payments should undoubtedly be extended to include older people – not to do so is discriminatory and deeply resented. They provide a way of achieving that choice and control for those older people who wish to use them (Barnes 1997). But those same principles of choice and control should guide all personal support services, irrespective of

who holds the purse strings. They should not be limited to those who wish to use direct payments.

The importance of domestic help to older people needs to be recognised. It is an essential ingredient of enabling people to continue to live in their own homes. There has been no policy decision to dispense with such services – they have simply 'fallen off the back of the shelf' as other pressures have supervened. They need to be dusted off and brought back.

Respite care needs to be more widely and consistently available, and preferred forms of respite actively developed, to ensure that older people are able to continue to remain at home without detriment to their quality of life, and that carers themselves get a break and an opportunity to replenish their energy.

Day services have become more narrowly focused on 'care' rather than inclusiveness – a fact which concerns Pensioners' Forums and other such representative groups up and down the country (Islington Pensioners' Forum 1997).

> *'The traditional services provided by day centres were seen as less satisfactory. The range of activities was perceived as restrictive and narrowly focused. However the opportunities for the development of networks of community resource centres were supported, particularly if management and control was shared by older people.'*
> (Henwood and Waddington 1998)

Day care should be one of the ways of enabling older people to retain their personal interests and their involvement in life and of creating new opportunities for involvement in the wider community.

Whether they are seen as part of preventative social care or of a wider housing maintenance agenda, minor home maintenance services need to be included too. Small household jobs can present an insuperable barrier to older people and be a cause of major worry and distress; this service should be extended to cover safety and security checks and action to remedy defects – accidents in the home are a serious hazard to older people and can easily precipitate a crisis.

New models of support

New models for older people's services do exist.

Very sheltered housing schemes like that developed by Extracare for Wolverhampton Council are one example and many housing associations are developing flexible 'housing with care' initiatives. They are able to offer much greater privacy and autonomy to tenants and enable people to retain their own lifestyles and possessions. The Extracare scheme is able to provide flexible support to allow for changing health and care needs, and offers a range of activities. A key feature is the extent to which the tenants themselves take responsibility for decisions about day to day running and management (Harding 1997).

But most older people would prefer not to have to move (HtA 1997), and there appear to be few examples of such inclusiveness and flexibility in the domiciliary care field. Instead, the nearest parallels are those communities, based in villages

or local urban neighbourhoods or on ethnic affiliation, where there are strong neighbourhood ties combined with local voluntary sector activity; but these are frequently not co-ordinated with more formal services and tend to have fragile funding, if any.

There is a tremendous amount that older people could and would do for themselves, given the right access to information and advice. When older people are consulted about their priorities, information invariably comes high on the list, since it is information that enables people to stay in control of their own lives and make their own decisions about the kind of help they need. But bald information without help and advice to hand is difficult to use effectively. Accessible community resource centres which both provide information and enable people to access appropriate help would have an altogether different impact, especially if older people themselves were centrally involved in planning and running them. Such resource centres could become a focal point in the community, putting older people in touch with a variety of forms of support and generating new initiatives where gaps and shortfalls exist.

One example of just such a flexible local home-based service for older people is Bournemouth Help and Care – a voluntary organisation which has developed a range of local services, from advocacy and the provision of information and advice to home maintenance and gardening, in response to demand from its clients. Grants to encourage and support such developments would be a relatively low-cost investment that could bring very considerable returns, enabling older people to remain in their own homes in much greater comfort and security

Potential for development

The public health Green Paper *Our Healthier Nation* envisages 'healthy neighbourhoods' as the locus for supporting older people. 'Partnership in Action' promotes close joint working between health and social services, with pooled budgets, lead commissioning and integrated provision. This new flexibility, and the potential offered by developments at primary care group level, could enable more effective and holistic responses to the needs and aspirations of older people – but only if health and local authorities and primary care groups recognise that potential and older people themselves are driving the agenda.

The establishment of the Better Government for Older People programme and the Inter-Ministerial Group for Older People, together with a renewed interest in the prevention of dependency within the Department of Health, are promising signs that the need for a holistic, enabling approach towards older people has been recognised by government. Better Government, in particular, is likely to produce a great deal of information and a greater understanding of strategies and practices for involving and supporting older people.

There is an urgent need to gather, evaluate and disseminate information about new models and forms of services and their effectiveness. Such information as we currently have is patchy and haphazard.

'New models and ways of enhancing the quality of life of older people are developing rapidly but not enough is known about them or their effectiveness. Policymakers, professionals and older people themselves all need information about what works and what

makes best use of resources, to drive their own decision-making. It should be widely disseminated through the media, the Internet and through training.'
(HtA/CGU 1998)

The government has proposed a new National Institute for Clinical Effectiveness, to guide just such a collection, evaluation and dissemination of information about effective medical care. A similar initiative is needed with regard to social care and the wider range of supports that older people need to remain independent.

It would be a further step in the right direction to establish a monitoring system with regard to all areas of public policy, whereby older people themselves had the opportunity to consider the barriers presented by current policies and the impact of proposed developments on their quality of life.

4. DO THE OBJECTIVES REMAIN RELEVANT?

The objective of enabling older people to remain in their own homes remains powerfully relevant. It is the aspiration of virtually all older people.

'"Home" has an enormously powerful emotional and psychological significance, especially for people who may have lived in the same house for many years, and few would relinquish their home without a struggle.'
(Henwood and Waddington 1998)

What the vast majority of older people want is to remain independent, in their own homes and in control of their own lives for as long as possible. Outcome criteria and performance indicators should reflect those objectives, rather than service-led criteria, if they are to have are to have a significant impact on the future development of services.

Older people are very clear about the outcomes they are seeking; they are realistic, and fully aware of where the barriers to those outcomes and the shortcomings in services currently lie. They need to be brought into the mainstream of planning and to have a strong voice both locally and nationally in working towards the realisation of their aspirations.

Acknowledgements

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