

*Social care services for disabled people*

## 6. Social Care Services for Disabled People

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Expenditure on health and personal social services takes the second largest slice of total public expenditure after social security. It represents just under one-fifth of public spending. The vast majority of this expenditure is on health services, with less than 20 per cent being devoted to local authority personal social services. It is not possible, and probably does not make sense, to disaggregate those elements of health spending which relate to people with disabilities. The OPCS disability survey (Martin, Meltzer and Elliot, 1988; Martin

**Table 6.1 Gross expenditure on core services for community care in Britain 1987/88 (£m)**

<b>LA Domiciliary Care</b>		<b>LA Residential Care</b>	
Home helps	533	Elderly	914
Meals on wheels	59	Younger physically handicapped	44
Aids and adaptations	49	Mentally handicapped children	52
Day care for elderly	77	Mentally handicapped adults	144
Day care for younger physically handicapped, mental illness, mentally handicapped	78	Mental illness	29
Adult training	167	<b>Total</b>	1,183
Social work	202	<b>Income Support</b>	
<b>Total</b>	1,167	For residential and nursing home care	774
<b>Community Health</b>		<b>Total Residential</b>	1,957
District nursing	261		
Health visiting	15		
Chiropody	44		
<b>Total</b>	320		
<b>Total Domiciliary</b>	1,487		
<b>Total Community Care</b>	3,444		

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and White, 1988) demonstrates that people with disabilities (as defined by the OPCS) are more likely than the general population to use general practitioner (GP) services and to spend time in hospital, and so the level of expenditure on general and community health services will be of considerable importance to them. The White Paper *Caring for People* (Department of Health, 1989a) gives the figures shown in Table 6.1 for gross expenditure on core services for community care in Britain in 1987/88.

These figures indicate that by far the majority of spending on community care is devoted to services for elderly people. Of course, the NHS also provides residential and day care for people in these various client groups, and spending on relevant hospital types for 1986/87 in England is given below. Even here it has to be borne in mind that many people in hospitals for people with mental illness are over the age of 65, as are over 20 per cent of people with mental handicap in hospital (Kiernan and Moss, 1990).

<b>Hospital Type</b>	<b>£m</b>
Long-stay and mainly long-stay	336
Geriatric	300
Mental illness	875
Mental handicap - hospital	470
Mental handicap - community units	24
Rehabilitation	5
Orthopaedic	51

Source: Department of Health, *Health and Personal Social Services Statistics for England 1990*.

If we focus on local authority personal social services net current expenditure as a whole, it can be seen that about one-third goes on services for children, just under half on elderly people, and around one-eighth on people with mental handicap (see Table 6.2). 13.5 per cent of total local authority expenditure on personal social services in 1988/89 came from fees and charges, compared with around 3 per cent of NHS income. Expenditure has risen in real terms throughout the 1980s, although there is debate about whether it has kept pace with increases in need, and with the rising cost of highly labour-intensive services (Evandrou *et al.*, 1990).

**Table 6.2 Local authority personal social services - net current expenditure 1987/88**

	£m	%
Children	993	33.2
Elderly	1,354	45.2
Physically disabled	172	5.7
Mentally handicapped	378	12.6
Mentally ill	74	2.5
Other	21	0.7

Source: Department of Health, *Health and Personal Social Services Statistics for England 1990*, Table 2.8.

Residential care for all client groups consumes one-third of the total local authority personal social services expenditure, and 50 per cent of expenditure on residential care is for elderly people. Of course, a substantial amount of residential care expenditure is now met through the social security budget, and this has a range of consequences which will be discussed in the following sections of this chapter. The first part of the chapter outlines the issues of management and organisation which are currently exercising the minds of people concerned with the provision of social care services. The ensuing discussion of residential care, day care and home care services provides an overview of the current situation for a range of disabled people, and illustrates why there is widespread support for change in the structure of service delivery. Participation and involvement by service users and their carers is identified as a key issue for the future, and some of the difficulties in applying a model of the service user as a 'consumer' in a market place are considered. Evidence about the implementation of the Disabled Persons Act 1986 is then reviewed for its implications in relation to impending changes in management and organisation.

### **Issues of management and organisation**

The Audit Commission (1986) drew attention to certain deficiencies in management, organisation and funding of community care which had the consequence of poor value for money and slow progress. The main points of concern were:

- (i) The build-up of community-based services was not keeping pace with the run-down of NHS long-stay hospitals. This was particularly acute in relation to people with mental illness. Despite run-down, the cost of NHS services for people with mental handicap and mental illness was increasing.
- (ii) The pattern of local authority services was uneven geographically. Services depended on where you lived.
- (iii) There was no overall reduction in the number of people living in residential settings. The growth of the private sector, fuelled by entitlement to receive financial help through income support, offset any reduction in NHS places. This latter entitlement provided a perverse incentive to enter residential care, for people who might potentially be supported in the community at lower cost.

The Commission felt that in areas where good practice was seen to exist this was despite the system rather than because of it. They recommended a rationalisation of funding policies from the centre, the removal of block-grant disincentives to the development of community care, short-term bridging funds to ease the transition from hospital-based to community care, the co-ordination of social security policies with community care policies, a more rational organisational structure with clearly defined authority and accountability and a greater degree of delegation to the local level, improved staff training and sufficient provision for 'cost-effective' voluntary organisations. As this chapter will indicate, most of the trends identified by the Commission have continued, even accelerated in some instances, although many proposed changes are in the air.

The Griffiths Report to the Secretary of State for Social Services (Griffiths, 1988), strongly influenced by the Audit Commission, recommended that there should be a Minister of State for Community Care, and that local authorities should have lead responsibility for the assessment and meeting of needs within their areas, combined with budgetary control over a specific grant which would be conditional on central government satisfaction with community care plans and priorities agreed by local and health authorities. It was recommended that local authorities should act as the designers, organisers and purchasers of care and not primarily as direct providers. Local authorities would assess the needs of people for residential care and

they, rather than social security, would meet the cost of this if needed. Savings from the social security budget would mean that money could be transferred to local authorities.

As is well-known, the government eventually produced a White Paper on community care (Department of Health, 1989a) which took on board some of these elements, but with a key and much-criticised difference: there was to be no specific earmarked grant, apart from a special grant for mental illness services, although there would be some transfer of funds to local authorities through the Revenue Support Grant. Key elements of the new managerial framework were to be:

- (i) the purchaser/provider separation;
- (ii) assessment and individual case management (perhaps with devolved budgeting);
- (iii) joint planning for community care by health and local authorities.

Key components of the new community care were argued to be:

- services that respond flexibly and sensitively to the needs of individuals and their carers;
- services that intervene no more than is necessary in order to foster independence;
- services that allow a range of options for consumers;
- services that concentrate on those with greater needs.

The House of Commons Social Services Committee produced a series of critical reports throughout the 1989-90 parliamentary session (House of Commons, 1990a-d). They constantly returned to the theme of the lack of an earmarked grant, pointing out the difficulties of planning new services without knowing prospective funding levels, particularly given that payments made for residential care through social security were widely felt to be inadequate even for that purpose (8th Report), and that 'the main determinant of consumer choice is the level of funding' (6th Report). They called attention to possible conflicts between the stated aims of choice and independence, and to conflicts of interest between users and carers. With regard to joint planning, they observed that changes in the structure of the NHS in 1991 would mean that District Health Authorities (DHAs) would be completely restructured in a way which might entail considerable difficulties in joint planning, since DHAs would no longer provide

services directly. Budget holding by some GPs would also complicate matters.

Case management and assessment will be discussed later in this chapter, but some of the possible difficulties with operating the purchaser/provider distinction through the use of contracts will be rehearsed here. Thomas and Towell (1990) draw on experience in the United States to stress the importance of authorities keeping some excess capacity under their own control. Failure to do this makes it very difficult to pull out of unsatisfactory contracts, especially in an emergency where, for example, physical or sexual abuse of clients is suspected. Decisions in such cases are complicated by the possibility that the provider might deny the allegations and sue after the event, when the necessary legal proof might be difficult to obtain.

Glennerster *et al.* (1990) also argue that authorities need their own powers to bargain with cartels of providers. Their study of research in the USA indicates that there are very few real competitors and that smaller and more informal organisations are driven out by the complexity of the bureaucratic procedures required in tendering for services. Large organisations under-cut rivals and then raise prices. Enforcing contract compliance is difficult because the measurement of outcomes is technically difficult and expensive. If frequent changes of provider occur, this is unlikely to be satisfactory from the point of view of clients who may prefer continuity of care. Finally, contractors may 'dump' difficult clients to cut their costs. Even at present, private and voluntary homes can be selective about clients, and some individuals, for example adults with mental handicap and severe challenging behaviour, are largely excluded from the non-statutory sector (except for very costly private hospitals).

The following three sections will consider the range of services, their costs, the pattern of provision and research evidence about their operation and effectiveness.

### **Residential care**

Table 6.3 shows how the cost of residential care varies for different types of service.

**Table 6.3 Comparative costs of residential care places by client group, gross cost per resident week (excluding capital charges)**

	1986-87	% change from 1985/86
<b>Local Authority</b>		
Elderly person	£123.33	7.4%
Physical/sensory handicap	£179.63	-8.9%
Mentally handicapped adult	£159.30	12.0%
Mentally ill adult	£155.82	9.2%
<b>NHS - Unit cost per in-patient week</b>		
Geriatric bed	£311.43	11.5%
Mental handicap hospital	£308.35	11.9%
Mental illness hospital	£273.35	10.2%

Sources: CIPFA, *Personal Social Services Statistics, 1986-87 Actuals*, Table 2; Department of Health, *Health and Personal Social Services Statistics for England 1990*, Table 2.7.

As Davies and Knapp observe (1988, p.293), these average costs hide considerable inter- and intra-authority variations, and also exclude opportunity costs associated with alternative uses of current provision. This latter point means that it may still be cost-effective to provide services in the community at somewhat higher rates than the average operating costs for residential care.

Total expenditure on residential services for younger people with a physical or sensory handicap fell by 23 per cent between 1986 and 1987, although the number of resident weeks of care increased by 20 per cent (CIPFA, *Personal Social Services Statistics, 1986-1987 Actuals*). As Table 6.3 illustrates, for this client group the gross cost per resident week decreased. The cost of residential care for all other adult client groups showed an increase in real terms (the rate of inflation was around 4 per cent over the relevant period).

### ***Changes in the pattern of residential care***

Are fewer people in the relevant groups living in residential care? For some client groups this is a difficult question to answer because overall estimates of the 'eligible' population are difficult to construct. For example, the last census to establish the number of people with mental handicap using services was carried out for the 1971 White Paper

(DHSS, 1971). The Audit Commission (1989) estimated that there were 124,000 adults with mental handicap and this suggests that between 40 and 50 per cent of the relevant population are living in some form of staffed residential facility. Leat (1988, p.129) suggests that around 5 per cent of younger people with physical disability are in residential care. In relation to the elderly, of course, chronological age is an easy division to use. The results are not greatly encouraging. In 1980, 66 people per 1,000 aged over 75 were in residential care, whereas by 1988 the figure had risen to 76 per 1,000. (Beds in geriatric hospitals are included in this definition of residential care. Omitting them, the figures are 47 and 60 per 1,000 respectively: Department of Health, *Personal Social Services Local Authority Statistics, RA/88/2*, para. 9).

Residential care itself can take many different forms, from large long-stay hospitals with up to 1,000 residents, to small, unstaffed but supported, group homes in ordinary housing. It is difficult to extract from published statistics the degree to which new forms may be becoming predominant, as opposed to a few highly publicised initiatives representing a mere tinkering at the margins of a largely unchanged mass of provision. Sinclair (1988b, p.39) identifies one of the characteristics of new forms of provision as decreased size. The average number of places per residential facility (excluding hospital places) has fallen for all client groups over the period 1978-88: for the elderly and younger physically disabled people from 31.6 places to 23.6; for people with mental illness from 17.4 to 13.7 places; and for people with mental handicap from 20.5 to 15.6 places. However, care must be taken in interpreting these changes. Table 6.4 gives a breakdown of these changes by source of provision and client group. In the private and voluntary sector, average places per facility have fallen for people with mental handicap and mental illness, but the decrease has been much less marked in the local authority sector. With respect to the elderly and younger physically handicapped people there has been hardly any change in the average size of residential care facilities, within each source of provision, although local authority premises are consistently larger than those in the voluntary sector, which in turn are on average larger than those in the private sector.

**Table 6.4 Average number of places per facility 1978-88**

	Source			Local Authority (unstaffed)
	Local Authority (staffed)	Voluntary	Private	
<b>People with mental handicap</b>				
1978	20.6	23.8	16.8	4.6
1988	18.9	14.1	12.1	4.0
<b>People with mental illness</b>				
1978	16.8	20.0	14.4	4.4
1988	15.6	14.9	11.9	3.6
<b>Elderly and younger physically handicapped people</b>				
1978	43.4	32.0	15.5	
1988	42.6	32.1	15.7	

Sources: Department of Health, *Personal Social Services Local Authority Statistics A/F 88/11a* and *RA/88/2*.

Of course, small size alone is not sufficient for quality. Indeed facilities for elderly people in the private sector have been criticised for having too little public space so that people may have to spend long periods alone in their rooms (Weaver *et al.*, 1985). However, it is clear that changes within particular sectors of provision have been less important in influencing the average size of facilities than changes in the overall pattern of provision by source. Over this period the proportions of residential care available from each source have changed dramatically, especially for some client groups.

Figures 6.1-6.4 show the changes between 1983 and 1988 in the pattern of provision of residential care by source and indicate the substantial continuing growth of the private sector, particularly for elderly people and for those with mental illness. As the Audit Commission (1986) observed, this growth has been largely unplanned and unregulated, and has led to widely differing levels of provision in different areas of the country, with, for example, seaside areas and certain other areas in the south of England relatively over-provided.

Table 6.5 gives an idea of the composition of the residential care sector in 1986, constructed from published statistics. This agrees

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Source: Department of Health, *Health and Personal Social Services Statistics for England 1990*.

*Disability and social policy*

Source: Department of Health, *Health and Personal Social Services Statistics for England 1990*.

reasonably closely, as should be expected, with the distribution found in the OPCS survey of communal establishments (illustrated in the pie graph).

Including hospital and community places, approximately two-thirds of all residential care in 1986 was designated for elderly people. However, as the 1985 OPCS survey of disability illustrates, places in other types of facility were also occupied by people aged 65 or more, to the extent that 80 per cent of all residents of communal establishments were aged 65 or more, and 67 per cent were aged 75 or more (Martin, Meltzer and Elliot, 1988). In a survey of public opinion about the most appropriate forms of care for people with different disabilities, West *et al.* (1984) found that two-thirds of respondents favoured residential care for elderly people suffering from mental disability, but only one in ten thought this was appropriate for people suffering from physical disability only. Unfortunately the

**Table 6.5 Distribution of residential places in 1986 (unstaffed provision excluded)**

		%
<b>Client group</b>		
Elderly	279,444	66.6
Younger disabled people	14,768	3.5
Mentally ill	68,511	16.3
Mentally handicapped	56,551	13.5
	419,274	
<b>Source</b>		
		%
Local authority	132,205	32.0
Voluntary	42,826	10.2
Private	98,243	23.0
NHS	146,000	35.0

Source: Department of Health, *Health and Personal Social Services Statistics for England 1990*, Tables 7.2, 7.3, 4.3.

OPCS survey does not allow us to discover how many people in residential care had physical disabilities only, because disability types overlap (Parker, 1990). Outside hospitals, the major provider of residential places for elderly people and for people with mental illness is now the private sector. Figures 6.1-6.4 which illustrated the changes in sources of provision for different client groups over the period 1983-88, do not include hospital provision, as this is not listed in the same way in available statistics. In 1986 the NHS provided 35 per cent of residential care, which, together with the 32 per cent provided by local authorities, still leaves the statutory sector as by far the largest provider. The NHS still provides by far the majority of residential care for people with mental handicap and mental illness.

### ***Research on residential care***

The most recent comprehensive review of research on residential care was carried out for the Wagner Committee and published as Volume II of the Wagner Report in 1988 (Sinclair, 1988a). In his article on common issues, Sinclair identifies a number of stakeholders with perhaps differing interests in residential care (Sinclair, 1988b). He observes that it has been widely argued that one purpose of residential care is to segregate certain groups of difficult, deprived or dependent

individuals from the rest of society. Some forms of residential care may also serve a function for the wider welfare system: in enabling elderly people to be discharged from hospital beds in the acute sector, for example. Relatives or other informal carers may be relieved of the responsibilities of continuous caring. Levin *et al.* (1989) suggest that carers' psychological distress decreases after the admission of their relative to residential care, although work by Challis and Traske (1990) indicates that it is possible to achieve similar reductions in carers' distress through suitable packages of supportive community services. Finally the residents themselves may be able to obtain a level of security, care and comfort not available elsewhere. In regard to this latter point, there is a clear gap in our knowledge of the evaluative opinions of residents in homes for people who are mentally handicapped or mentally ill. Such evidence as exists in relation to people who are elderly or physically disabled suggests that many become residents reluctantly, and without careful prior planning, in a context in which they feel they have no real alternative choice.

Common criticisms of residential care identified by Sinclair centre on the difficulties in achieving anything approaching a normal or reasonable life, especially in a large communal setting (Sinclair, 1988b). Traditional forms of residential care have not proved effective in developing skills required for normal living or in ensuring that residents have opportunities for choice and a degree of control over their own lives (Willcocks *et al.*, 1982, 1987; Alaszewski, 1986; Booth, 1985). Finally, it is often argued that the cost of residential care is high compared with the potential cost of suitable alternative care in the community. This issue will be explored in more detail below.

### ***Comparing costs of alternative forms of care***

Of course there is no firm dividing line between residential care and care in the community. Indeed, for different groups of clients these terms are used in different ways. Thus community care for people with mental handicap has most frequently been used to mean care outside a hospital, usually in some kind of residential facility in the community, whereas for elderly people, community care has usually been interpreted to mean living at home with a package of support services, as opposed to living in some form of residential facility. Thus a question such as 'Is care in the community more expensive

than residential care?' does not have quite the same meaning or answers for different client groups.

In 1986 the Audit Commission offered some illustrative costings of alternative packages of care for an elderly person and a person with mental handicap. These indicated the conflicts between social security, NHS and local authority funding priorities, in that in most options the costs to individual agencies were not related to the costs to the public purse overall. The Commission wished to press the point that money was readily available to fund some of the higher-cost institutional options, in the form of social security payments for residential care in private and voluntary homes, whilst potentially cheaper community-based options were starved of funds. The argument that this perverse incentive to take up residential care was making increasing demands on the social security budget is well-known and needs no further elaboration here. The White Paper *Caring for People* (Department of Health, 1989a) contained a graph which illustrated that the upward path of social security expenditure on residential care homes and nursing homes has continued since 1981. The total spent in this way has risen from £10m in 1979 to £1,000m in 1989, and this is described in Chapter 1 of the White Paper as one of the government's 'key achievements' in relation to community care services.

### ***Hospital and community care costs compared***

The general illustrative costings referred to may give rise to an impression that community care is a cheap option. The Audit Commission (1986) used information about average costs drawn from official statistics (of the kind which have already been quoted in this chapter). Of course, as the Commission recognised, average costs do not reflect variations across individuals or settings. It is possible that hospital care might be cheaper for some individuals even if average costs were higher. It would only be meaningful to compare average costs of two types of service if the dependency characteristics of the populations within them were identical. The OPCS disability survey indicates that in many respects NHS facilities contain people who apparently suffer higher levels of disability (Martin, Meltzer and Elliot, 1988).

In a review of studies of comparative costs, Shiell (1990) draws attention to this and a number of other difficulties in assessing such

costs. For example, the run-down in hospital beds will increase average costs because fixed costs are spread over fewer patients. Also community-based facilities draw on a wider range of resources whose costs should be included if cost estimates are to be comprehensive. Finally, the relationship between quality and costs must be central to any process of decision-making which is concerned with efficiency. Shiell cites a range of studies which seem to indicate that NHS facilities based in the community cost more than hospital places, although other community facilities may be cheaper than hospital. With regard to the resettlement of people with mental handicap, Korman and Glennerster (1990) found that the estimated cost of community reprovision was 57 per cent more than a median estimate of the costs of continuing care in hospital.

Results by Knapp *et al.* (1990) from the Care in the Community initiative show that community placements were 17 per cent more expensive than hospital care. Only residential homes and sheltered accommodation were not more expensive. Comparisons in this latter study were between the same clients as they moved from one kind of care to another, and measures of quality suggested that community options did have more positive outcomes, although in a minority of schemes there was an increase in behavioural difficulties. Shiell concludes that, in comparison with hospital care, community living appears to be in the main more costly, and more effective. Whether an equivalent amount spent on hospital care would lead to equal effectiveness is a question which cannot be finally answered, because it would undoubtedly involve making judgements about the relative importance of different dimensions of outcome. Comparisons between community services delivered to the person's own home and residential care will be considered later in this chapter.

### ***Residential care in future***

Sinclair (1988b) identified a number of key strands in new thinking about residential care. In current favour are: smaller size, location within the community, linkage with a network of services, an expansion of opportunities for undertaking valued social roles, and individual-orientated management practices rather than block treatments. Subsequent work has laid an even greater emphasis on the importance of residents' views, at least in theory. In the Social Services Inspectorate's *Guidance on Standards for Residential Homes*

(Department of Health, 1990b) it is stated that 'placing the people who use the service in central position' is a primary theme of the document. But will this guidance and information for service providers be effective in achieving change? Have the real likely costs of obtaining residents' views been considered? The Social Services Inspectorate (SSI) states that interpreters and advocates may be necessary 'for some people'. The OPCS stated that they were unable to interview 70 per cent of people in communal establishments. Techniques for obtaining and interpreting expressions of opinion or evaluation, for example from people with severe mental handicap, can be developed but will take time and resources to implement. Also, residents have an uncomfortable capacity for not wanting what we think they ought to want. For example, in a survey of residents in 100 local authority homes, a majority of elderly residents who expressed a preference wanted their chairs lined up against the walls and not placed in sociable groups; only one-third of residents wanted a residents' committee; only a quarter wanted to choose the wallpaper and paint in their rooms (Willcocks *et al.*, 1982).

Lest we may wish to argue that people have become socialised into an acceptance of their current social and physical environment, and may need assistance to return to a situation where they can make choices, it should also be noted that three-quarters of residents wanted a single room, most expressing a preference for a bed-sitter to which they could return during the day, and most wanted control over their immediate environment, for example the temperature of their bedroom (Peace *et al.*, 1979; Willcocks *et al.*, 1982). Unfortunately much of existing residential care is not constructed in this way, and could not become so without considerable expense. Where will the resources be found to bring residential care up to the standards required by residents? It seems unlikely that the process of participation will in itself increase satisfaction. Peace *et al.* (1979) reported that greater choice over some aspects of their lives was not related to satisfaction among elderly residents. Canter *et al.* (1981) reported a slight negative relationship between participation and feelings of satisfaction among younger people with physical disabilities.

With regard to the future, the Department of Health has set up the Caring in Homes initiative which is designed to develop models of good practice in residential care across a variety of regions, client groups and service providers. The views of residents, their families

and carers, it is said, will play a part in development and evaluation. The models developed will be evaluated, in relation to their capacity to improve residents' quality of life, and will cover staff training, links between homes and community, quality assurance, information needs and complaints procedures.

### **Day care**

Table 6.6 indicates the current extent of provision of day care.

**Table 6.6 Day centre places for people with mental handicap, mental illness, elderly people and younger physically handicapped people 1989**

	Places
Client group	
Elderly people	24,491
Younger physically disabled	8,471
Mental handicap	54,221
Mental illness	9,078
Mixed centres	18,248

Source: Department of Health, *Personal Social Services Local Authority Statistics A/F 89/8*, Tables 1, 2, B.

Note: The figure for mental illness includes 2,682 provided by voluntary organisations and others.

It does not seem to be possible to disaggregate day places into those provided by the statutory, voluntary and private sectors. It is generally accepted that the current contribution of the private sector to day services is minimal. If it were thought to be desirable to know the source of the services, as opposed to the funder, then the collection of the statistics would have to be revised. The largest group of consumers of day care are people with mental handicap. As well as the previously observed decline in spending on residential care, there also seems to be a relative decline in the number of day places available for younger people with physical disability. Department of Health Local Authority Statistics show a 16.6 per cent decline in day places for this group over the ten years 1979-89, although, in total, day places provided by local authorities have increased by 25 per cent over the same period. The apparent decline in places for the younger

physically disabled may be explained by a greater propensity to place them in mixed day centres; however, there appears to be no way of investigating this from the given statistics. The Audit Commission (1986) made the assumption that places in mixed centres could be allocated *pro rata* in accordance with the relative numbers of places in centres designated for single groups. If this assumption held, then the rate of decrease in places for young people with physical handicap would be even larger at over 30 per cent. With the exception of places for this group, the number of places in day centres has shown a steady growth throughout the 1980s. There are, however, substantial regional variations; for example, a comparison of day places for people with mental handicap across different types of local authority indicates relatively much lower provision in London (see Table 6.7). The same is true for residential places for mental handicap.

**Table 6.7 Day places for people with mental handicap at 31 March 1989**

	Rate per 1,000 pop. (aged 16-64)	Places
<b>Type of authority</b>		
Shire counties	13.4	32,703
Metropolitan districts	12.6	15,038
Inner London	1.3	2,024
Outer London	1.6	4,456

Sources: Department of Health, *Personal Social Services Local Authority Statistics A/F 89/8*.

In contrast to the figures for mental handicap, the two London regions had residential and day provision for people with mental illness which was substantially higher than for other regions (Department of Health *Statistical Bulletins* 3(4)89, 3(2)90).

### ***Cost of day care***

The Audit Commission in 1986 gave estimates of £38 per week for day care for an elderly person and £46 for a person with mental handicap. In an appendix to the *SSI Inspection of Day Services for People with a Mental Handicap* (Department of Health, 1989b), Wright and Tolley outline a procedure for costing day services, the results of which illustrate the considerable variation in costs across different centres and different authorities. It is to be expected that

places in Special Care Units would be more expensive than places in Adult Training Centres generally, but even taking account of this, cost variations were evident across and within the eleven local authorities studied in depth. Wright and Tolley's costings vary from £39 to £91 per attendance week (excluding one special needs centre which cost £155 per week). Within one authority costs varied from £39 to £70 per week.

### *Quality of day care*

The SSI Inspection raised a number of more general issues in relation to the organisation and quality of day care. The findings revealed a lamentable lack of clear understanding of the purpose of day care provision and, despite some good practice, a general failure to implement care planning based on careful assessment.

Particular points included: poor record keeping; failure in many cases to link assessment coherently to any plan or framework of activities; lack of specified objectives for the service, with few written policies or guidelines; a lack of formal induction programmes and a need for training at all levels, especially since many staff were not qualified. The Inspectorate also observed that contact with families seemed to be unstructured and non-purposeful; there was limited involvement of carers and clients in planning, and little work on self advocacy.

The SSI report itself is open to some of the same criticisms which were levelled at Adult Training Centres. Although it is stated that Inspectors talked to clients, there was no systematic attempt to collect clients' views, and certainly no report even of any client comments. Equally there is no systematic information on client/user participation in the management of centres, although this is said to happen in 'some' centres. Were clients anxious for a comprehensive assessment of their needs, and a detailed plan based on this? In a recent study of user participation in planning a resource centre for disabled people, users insisted that no form of assessment should be imposed on people who wished to use the centre (Wensley, 1989).

Questions of unmet need for day services were not addressed by the Inspectorate, despite the fact that substantial variations in provision by area are known to exist, and the exclusion of certain groups, such as people with profound handicap (Audit Commission, 1989) and people with challenging behaviour (Blunden and Allen, 1987), is

known to occur. The SSI appeared to be satisfied by social services departments' (SSDs') claims that they felt they should be meeting the needs of all, despite there being no statutory obligation to do so. Another untouched issue which is arousing current concern (Newnham-Walsh, 1988) is the question of gender bias in the allocation of tasks or type of training among clients in ATCs. For example, women may be allocated work in the laundry, whilst men work in carpentry. Equal opportunities have hardly begun to be considered in this context.

### **Domiciliary care and home care**

During the 1980s there have been considerable increases in expenditure on standard domiciliary and home care services, particularly the home help service, although of course the population making most use of these services has also been expanding during this period. A number of papers and articles were published in the early 1980s which criticised domiciliary and day care services for inflexibility and poor targeting (Goldberg and Connelly, 1982; Hurley and Wolstenholme, 1979). There were also criticisms that services were delivered in ways which promoted dependency, reinforced prevailing gender divisions among carers, and discriminated in favour of elderly men in the provision of domiciliary assistance (Walker, 1982; Charlesworth *et al.*, 1984; Carpenter and Paley, 1984). Whilst confirming a degree of apparent gender discrimination in the provision of domiciliary services, later work has indicated that assessment appears to be influenced to a greater extent by the marital status of available carers and whether caring is part of a marital or filial relationship (Arber *et al.*, 1988; Qureshi and Walker, 1989).

Given the greater resources devoted to domiciliary care, and changes in service organisation designed to promote greater flexibility, the PSSRU domiciliary care study was designed to investigate the effects of changes in domiciliary care across a range of local authorities. Reporting on the results of this study, Davies and Knapp (1988) argue that 'there is little sign that many of the beneficial effects one might postulate are in fact there' (p.337). There were few measurable effects in terms of outcomes where there had been above-average increments of spending, and differences in the volume of home care services did not appear to affect the morale of clients. It

has been suggested that a more radical change in the structure of services is required to enable measurable improvements in outcome.

The Kent Community Care Project (KCCP) (Challis and Davies, 1986) is probably the best known attempt to assess the costs and outcomes of providing packages of support services in the community for elderly people on the margins of need for residential care. It is well-known that the demonstrated effects were substantial, with the experimental services proving cheaper than standard services for most, but not all, clients, and outcomes in terms of death, admission to residential care and morale of elderly people all being superior in the experimental group. As initially conceived, the project was essentially an experiment in devolved budgeting, which aimed to increase efficiency by giving front-line workers control over resources and knowledge about the costs of the services which were allocated to particular clients. It often seems to be thought that this experiment demonstrated the advantages of case management, but whilst it *may be* that case management was a necessary condition for the successful implementation of devolved budgeting, the KCCP certainly does not prove this. Nor does it prove that case management without devolved budgeting would enjoy anything like the success of the KCCP or its replications.

The term 'case management' has raised objections in some quarters for its overtones of professional imperialism, and the SSI has recently decided to talk about care management instead. Unfortunately this seems to blur a useful distinction between management of resources, and planning, at a strategic level (care management) and individualised service planning. Nonetheless, objections to the term are understandable: the Disablement Income Group in evidence to the Social Services Committee described this as 'another tier of authority' over disabled people. A preference has been expressed for a case manager as someone working in partnership with a disabled person, in a role akin to a knowledgeable advocate who is independent of any particular service agency.

Challis and Davies (1986) were clear that the case manager should be integrated into the providing agency, although it was claimed that service planning was carried out, where possible, in partnership with the elderly person and his or her carers. The community care White Paper, of course, requires decisions on service provision after assessment to take account of what is 'available and affordable'

(Department of Health, 1989a, p.20), which would seem to fit uneasily with the idea of a case manager as an advocate for the client, especially in a context of limited resources. As the Social Services Committee (House of Commons, 1990a-d) pointed out, case management in itself is no substitute for services. There is a developing literature on the difficulties that would be involved in getting arrangements for more widespread case management in place (Fisher, forthcoming), the training needed for staff who are to undertake this function, and the costs of the processes of assessment and case management (Challis *et al*, 1989). It may be instructive to consider what has happened in relation to the implementation of section 4 of the Disabled Persons Act (1986): the duty to assess need on request. The SSI (Warburton, 1990) reported that some departments warned that, because of resource constraints, assessment might not be followed by action. A variety of attitudes to this issue emerged, ranging from an expressed belief in the necessity of changing staff attitudes so that they assessed in relation to need instead of available services, through to a belief that assessment on the basis of what could be provided was the only realistic way forward.

Not surprisingly, it appears that the government wishes to see priority given to operating the gatekeeping function in relation to entry to residential care. Draft guidance on assessment and case management, issued by the Department of Health, states that 'priority should be given to having in place by April 1991 arrangements for assessing the needs of people applying for residential or nursing home care who, but for the benefit changes to be introduced on that date, would have been supported through social security benefits in independent residential care or nursing homes' (Department of Health, 1990a, pp.1-2). In the short term this may increase the incentive to enter residential care rather than remain at home. People on low incomes seeking residential care may wish to beat the deadline, especially if they have any doubts about their eligibility in terms of level of disability.

Of course it has not been demonstrated that the cost and quality advantages of case management and devolved budgets would be maintained if they were to be applied to other groups of disabled people, particularly if they were not on the margins of need for residential care. However, it seems entirely possible that the quality advantages would remain. It would be instructive to see some

experiments evaluated on these lines. Equally, it would be of interest to investigate devolving budgets to clients themselves, in some instances, for their own management. Where disabled clients do not suffer impaired mental functioning and are not 'unwilling' users, there seems to be no reason why case management should not involve their explicit participation and require their agreement in care planning. There may be little scope for such devolution when working with elderly people suffering from dementia, but there are considerable possibilities with other clients. Sally Baldwin and Gillian Parker, in their chapter in this volume, outline some of the preliminary evidence available about the advantages and potential difficulties which might be involved.

### ***Unmet needs***

Volume 4 of the OPCS Report (Martin, White and Meltzer, 1989) covers the use of health and social services. It concentrates on listing the services people were getting, and on what they said they needed. The survey questions about needs were constructed in terms of needs for named services, and so the information about unmet needs is specifically a measure of expressed demand for particular services.

Mobility and transport are not treated in the same way. There is no link with any information on, for example, the mobility allowance. A majority of disabled adults felt that they could not go out as far or as often as they would like. This included 59 per cent of those who were able to go out alone, and 88 per cent of those needing assistance to go out. It is difficult to tell how much of this difficulty could be alleviated by the provision of suitable services. The disabled people who were able to go out were apparently most likely to say that any difficulty was a consequence of the effort and pain involved in doing so, rather than transport problems. But, if going out is too much effort, why is this? Silburn (1988) identified transport and access as key needs reported by disabled people, and certainly the OPCS survey indicates that the majority perceived this as an area where they were unable to fulfil their own wishes. There is no information about access in the OPCS survey reports. In the chapter on services, far fewer people expressed a need for any particular service or group of services, although areas of high unmet expressed need were identified within particular sub-groups.

**Table 6.8 People living in private households – per cent in each age group having contact with professionals in past year**

	16-49	50-64	65-74	75+	All
Social worker	10	6	6	6	7
Home help	2	4	12	31	14
(Private dom. help)	2	2	3	7	4
Voluntary services	0	0	0	1	1
Meals on wheels	0	1	2	9	4
Consultant	51	51	45	39	46
Physio	12	13	10	8	10
GP	75	84	82	84	82
Chiropody	2	5	10	22	11
Home visits	6	3	7	10	7
Community nurse	9	9	14	26	16
In hospital	20	18	19	18	18

Source: Martin, White and Meltzer (1989), Tables 4.1, 4.19, 4.31.

Tables on contact with relevant professionals held few surprises (see Table 6.8). People with disabilities were more likely than the general population to have been in hospital in the past year, particularly if they were in higher severity categories.

Given the high levels of contact with health professionals, it is not surprising that people were most likely (38 per cent) to say that they would approach health service personnel to find out about services, although 25 per cent said they would approach SSD personnel. People were asked whether they experienced a shortfall in services of treatment received at home, and overall 14 per cent said that they did. Half of these were already receiving some services. It appears (*ibid.*, Table 4.33) that 71 per cent of those who felt they needed more home services had not asked anyone for them. Given their high levels of contact the opportunity would seem to have been available. Perhaps we need to understand more about why people do not ask for services they think they need, or why professionals do not pick up and respond to these particular needs which were freely expressed to an unknown interviewer with no services to offer?

Assuming that those in the final three categories in Table 6.9 represent those who need home services, this suggests that there is some unmet need among one-third of all disabled people with any requirement. This is a fairly crude indicator because it involves

**Table 6.9 Summary results on unmet need for home care services**

	All	Category 9-10
Had not received - no expressed need	57%	18%
Had received - no expressed need for more	29%	59%
Had received - expressed need for more	7%	19%
Had not received - expressed need	7%	4%
<i>Base:</i>	10,000	670

Source: *Ibid.*, Table 4.26.

defining need as either expressed demand or existing service provision. Among the most severely disabled, fewer are not reached at all, but 28 per cent of those who receive or want services express unmet needs.

One problem in interpreting the tables is that, because such a large number of people have been identified as disabled, the percentages experiencing shortfall in particular services may be very small, and cannot easily be judged in relation to the total numbers who may be receiving that service. To give an example, 8 per cent of those who wanted more services expressed a need for laundry services; this rose to 13 per cent of those in severity category 9-10. However, if we refer to tables indicating services received, then it appears that only 3 per cent of people in this severity category actually receive a laundry service. In fact this suggests a severe failure to meet the expressed needs for a laundry service of people in the highest severity category – a great many more people want this service than actually receive it. The same is true of night-sitting services. In contrast, we know that 14 per cent received home help and that approximately 3 per cent wanted more (or some) home help. In this case it may be supposed that unmet need could be met by an expansion, or more efficient redistribution, of the service, whereas in the case of laundry and night-sitting services these would almost have to be created from scratch.

A number of tables in Chapter 5 of the report give the proportions of relevant sub-groups who expressed a need for particular aids and other equipment or facilities. Among these are:

## *Disability and social policy*

Mobility	7%	
Vision aids	13%	
Hearing aids/equipment	29%	
Incontinence aids	17%	
Aids for dexterity	23%	
Personal care equipment/furniture	31%	
Home adaptations	42%	(of those with personal care disability)
	35%	(of those with locomotion disability)

This testifies to a considerable shortfall in the provision of resources which can compensate for disability. The picture in residential homes reveals them to be even more disabling. People living in establishments are more likely to have access to special furniture, aids to personal care and to protective bedding for incontinence. However, they are less likely than those at home (controlling for particular types of disability) to have access to talking books, braille equipment, hearing aids and optical services. They are also less likely to have social outings, visits or holidays. This ties in with other research indicating, for example, considerable undiagnosed hearing problems in people with mental handicap in residential care, and problems of access to optical services among elderly people.

Another way of looking at unmet needs in the OPCS survey is to consider the information on whether disabled adults feel that there are items which they need but cannot afford to buy. Around one in four people thought they needed to spend more but could not afford to (Martin and White, 1988, Table 4.19). The items most commonly mentioned as needed were fuel, clothing, bedding and food. It seemed that longer-term expenditure such as paying for repairs or decorating and the replacement of furniture was also a perceived need. Expenditure on special items or home services was considerably less than additional expenditure on normal items, although people in severity categories 9 and 10 spent more on home services and treatment than others (20 per cent of their extra spending was for this compared with an average of 10 per cent).

### **User participation and involvement**

There are various levels at which service users and carers may be involved in social services:

- (i) individual level – people being involved in the planning and evaluation of their own services;
- (ii) operational level – people being involved in the running of service facilities which they attend, or in which they reside;
- (iii) strategic level – people being involved in the strategic planning of services across a wider area.

A number of difficulties have been identified in applying a model straightforwardly drawn from the ideas of the consumer, and the market place, to the users of welfare provision. Some of these will be briefly considered below.

### ***Individual level***

*Unwilling users.* This area of argument has been developed particularly in respect of child protection (Fisher *et al.*, 1988), although it clearly can apply to other groups, for example people detained under the Mental Health Act. It is linked to the social control function of welfare provision, and can lead to the argument that consumer 'satisfaction' may not be the most relevant area of outcome, even from the point of view of users themselves (Fisher, 1983). The discussion is valuable in drawing attention to the essentially unequal power relationship existing between service users and providers.

*Incapable users.* Undoubtedly, substantial numbers of users suffer impaired mental functioning: 26 per cent of people in communal establishments suffer from senile dementia (Martin, White and Meltzer, 1989). Equally, ways are being developed to try to overcome our difficulties in understanding expressions of opinion by, for example, people with mental handicap who have limited speech (Prosser, 1989; Simons *et al.*, 1989). It remains true that these techniques are likely to be costly to apply, calling as they do for a more unstructured, individualised approach to collecting information. The use of advocates and interpreters also cannot be achieved without cost and may meet with resistance from staff.

*Separating the needs of users and carers.* Conflicts within informal networks have often been identified as an issue in studies of elderly people and people with mental illness (Lewis and Meredith, 1989; Qureshi and Walker, 1989; Perring *et al.*, 1990). Grant (1985) found that some elderly parents had become dependent upon the income from benefits which their adult children with mental handicap

were able to claim, in a way which might be a disincentive to supporting a move away from home by their child. Hogg, Moss and Cooke (1988) also suggested possible differences of opinion between elderly parents and their mentally handicapped children over the issue of leaving home. Grant (1990) recently went so far as to suggest that carers' and users' participation should be separate at all levels. Parents may feel that they have been managers of their child's care for years and that services have not established a right to take on this role, but have been conspicuous by their absence.

*Satisfying other stakeholders.* Sinclair (1988b) observes that researchers may seem more dissatisfied with services than users appear to be. It is often suggested that, for example, elderly people do not want enough from services, implying that we as a society should require higher standards. On the other hand, it is clear that some users are thought to require too much. Qureshi *et al.* (1990) report an instance in which a middle-aged man, living in a facility for people with mental handicap, resisted attempts to teach him self-care skills because he had a clear preference that others should undertake his 'domestic servicing'. Staff did not feel that this preference should be met, although of course it might be argued that for many middle-aged men a 'normal life' provides precisely this.

### ***Operational level***

*Disproportionate participation by some groups rather than others.* For example, this has been noted for men in elderly persons' homes (Hockey, 1989), and for the more intellectually able in day centres for people with mental handicap. At this level some structure of elections and accountability to users is at least possible (Crawley, 1983).

*Uncongenial nature of committees and meetings.* This was mentioned by McGrath (1989), in relation to the All-Wales strategy for mental handicap. Crawley (1983) indicates how people who lack experience in participatory structures may require assistance to establish and maintain user influence in day centres for people with mental handicap.

*Other stakeholders.* Users may wish to operate policies which conflict with those of the providing agency. They may wish to exclude other users in ways which may cut across equal opportunities policies, or stigmatise other groups. Examples which I have come across in practice include one where physically disabled users wished to

exclude elderly and mentally handicapped people from a resource centre for disabled people, and another where elderly people did not wish their day centre to include people with mental handicap. Users may not wish to be assessed, but simply to choose whether or not to attend a service facility.

### ***Strategic level***

*Representativeness, accountability to other users or carers.* This is the key difficulty for users at this level although it may not be a practical problem until they wish to suggest something that other stakeholders do not agree with. Users can find their position strengthened by having available the results of research which reflect a wider range of users' views. They may even wish to see research undertaken to investigate whether there is widespread support for particular service developments or changes. Grant (1990) reported that it was possible for some carers to become so 'over-used' by the demands of participation at this level that they feared losing touch with their original constituencies and absorption into the bureaucratic system. All the points mentioned under earlier sections about the uncongenial nature of formal meetings, the need to separate users' and carers' views, and satisfying other stakeholders, apply with equal force to this level of participation.

### **Will the new structures improve capacity to meet needs?**

In 1989 the Social Services Inspectorate carried out an inspection into the extent to which social services departments were operating those sections of the Disabled Persons (Services, Consultation and Representation) Act 1986 which had been implemented (Warburton, 1990).

It identified many ways in which the objectives of the Act were not being met: variations across authorities in their degree of willingness to commit funds to personal social services, and in their levels of service to particular client groups; difficulties in inter-agency co-operation; poor information for carers and clients; and a gap between intentions and practice with regard to the direct participation of users. These problems are all relevant to the proposed changes in organisation and structure outlined in *Caring for People*.

In their 8th Report on *Community Care: Planning and Co-operation*, the Social Services Committee said (House of Commons, 1990d, para. 15):

The multiplicity of statutory, voluntary and private providers already involved in the provision of community care services means that understanding the potential outcome of the planned organisational and structural changes, and the likely changed relationships between authorities and providers is very difficult. By comparison the NHS is a comparatively straightforward, albeit vast, structure.

I do not intend to try and predict the outcome of the changes (whenever they may be implemented). I would, however, urge the importance of systematic measures of the outcomes of any changes. The avowed objectives are to meet the needs of individuals and their carers, foster independence, increase choice for service users and their carers, and target resources on those with greatest needs. But will those objectives be achieved?

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