

# Developing social care: the current position



## Chapter 7: People with physical disabilities

### 7.1 Introduction

This chapter was the last of the five service user group chapters to be written, and it is the shortest. One reason is the limited time available to us. Another is that some of the contextual and background material is covered in other chapters, particularly those concerning older people and people with learning disabilities. (By this last remark we do not intend to imply that the issues are identical, and certainly not that the needs and preferences of individual service users – or the issues raised by them - are identical. Rather, there are some commonalities and some generic trends that mean that a full repetition of some discussions is unnecessary.) A third reason for this chapter being relatively brief is that we have found much less evidence to describe developments, structure discussion and inform argument.

We are not sure why we should have uncovered so little. One search strategy may have been deficient. We designed our electronic trawl through the literature, carried out hand searches of key journals and contacted researchers with a particular interest in physical disability and social care, but there may have been 'grey' literature in this field that we missed. Another possibility is that the template we have employed to search for, discuss and structure the evidence does not fit the physical disability field, or at least the research conducted in it. A third possibility is that much of the research that *is* conducted does not very directly concern social care. There is, for example, a substantial literature on the care and treatment for people who have had a stroke. In some of our own previous research we have spent some time reviewing the literature, and have contributed to two major and other minor published studies, one of them evaluating a training and support programme for carers. But we have found little in that literature base that could be described as having an exclusive or dominant social care focus. Rather we would characterise those studies as belonging to the medical field – in terms of orientation, 'model', focus, outcome, dimensionality and services delivered.

In consequence this chapter is structured slightly differently from chapters 4, 5, 6 and 8 on the other service user groups. We briefly describe the policy context (although we can rely a great deal on other chapters to provide much additional detail) and discuss the needs of people with physical disability. At this point we are able to introduce some of the national data for England, Wales and Northern Ireland. (We believe that we have covered the national data collections comprehensively.) We would accept the criticism that our discussion does not adequately engage with a social model of disability, but that is not – in the main – how we found the evidence on social care. Section 7.4 looks at expenditure levels and trends, but we have not sought to cover the evidence or issues relating to welfare benefits and similar. We then offer some brief comments on resource inputs. We have not had time to review the literature on the carers of people

with physical disabilities. The next section (7.6) is concerned with services and we describe trends in a similar way to other chapters, although in less detail.

And there the chapter ends. We do not offer separate sections on outcomes and cost-effectiveness or on choice. We have found a little evidence, and we have included it in other sections of the chapter. However, we would imagine, despite our search efforts, that there is more research evidence than we have been able to locate and we would prefer not to offer only a partial review. (We have recently found more evidence but there is not time for us to assimilate it into the chapter.) In the other four service user group chapters (older people, mental health, children, learning disability) we are confident, because of our own research experience in each field and our familiarity with issues, researchers and research, that we will have covered most of the relevant evidence. We simply do not have that familiarity or confidence in the physical disability field.

## 7.2 Policy context

The group of people with physical disabilities is obviously very heterogeneous. The common image of someone permanently in a wheelchair represents only a minority of the total. Some disabled people are temporarily impaired through injury; some are disabled since childhood and some will have recently developed a condition that is likely to be long-term. Being able to distinguish these 'disability trajectories' is essential to avoid melding what may be very different experiences, and is obviously very necessary in order to design, implement and evaluate effective social care and other policies and practices.

### Pre-1990 context

Both the Chronically Sick and Disabled Persons Act of 1970 and the Disabled Persons Act 1986 sought to introduce changes to care systems so that they were better able to address the needs of people with disabilities. Local authorities were to act as the lead agencies. The 1986 Act was intended to facilitate a better match between need and provision so that all people with disabilities, including young adults, would receive a more co-ordinated service. However, as is well known, many of the intended changes set out by the 1986 Act never took place, mainly due to lack of resources.

The Independent Living Fund was introduced in 1988 at national level for people with disabilities, comprising a state charitable trust to provide cash for care assistance in the community. The financial support was generally used to buy in essential services, such as home help and personal assistance (Kestenbaum 1992). The Fund was established

for five years. From 1993, much more restrictive criteria for entry were introduced, with local authorities given responsibility (under the 1990 Act) for assessing needs.

## The 1990 Act

We have discussed the aims, implementation and some general limitations of the 1990 NHS and Community Care Act in other chapters and do not go into detail here. The Act sought to enable people to live independent lives in the community for as long as they were able and wished to do so, an objective that has remained central to policy for disabled people, although also one whose achievement has been limited. The importance of effective assessment for physically disabled people was emphasised, as the capacity to maintain independence was likely to be influenced by the subsequent provision of aids and services. The Act represented a shift in favour of consumer interests in social care services, through encouraging user and carer involvement in the processes of assessment and in determining appropriate services, and by requiring social service authorities to consult with users.

During subsequent years, disability issues appear to have risen up the political agenda, due in no small measure to the activities of the 'disability movement'. There have been a number of policy initiatives focused on disabled people of working age. The 1995 Disability Discrimination Act, covering people with disabilities and enduring health problems, contained provisions on employment, access to goods and services, and the buying or renting of property. The Disability Rights Commission was set up to monitor its operation.

## Developments since 1997

To some people, the election of a Labour government in 1997 brought the opportunity to make the shift from market competition as a key lever for service improvement towards a reassertion of (new) public service values. There was, for example, a rediscovery of community development as a resource for regeneration and to contribute to local health improvement initiatives. Another emphasis, as we have seen in other chapters, was the promotion of partnership working (Kersten *et al.* 2000, Barnes 1998).

The government's programme for disabled people was set out in the 1998 White Paper *Modernising Social Services*. It aimed to:

- help people to live as independently as possible and improve their quality of life;
- create fairer and more consistent services;

- develop services that respond to the expressed needs and objectives of disabled people;
- guarantee that services fit the needs of individuals; and
- maximise the control that people have over the services they receive (Clark 2003).

Government policy is centred around promoting opportunities for people to live in their own homes rather than in hospital or a care home. As part of the new welfare reform agenda, the New Deal for Disabled People was launched in 1998. This was part of a programme of government initiatives aimed at helping those receiving incapacity benefit into work. Shortly after, the 1999 Welfare Reform and Pensions Act overhauled some of the main disability benefits.

Also relevant to the policy context are the best value requirements of the Local Government Act 1999, the national carers' strategy, the NSF for Older People, the Better Government for Older People initiative, and of course the strong themes of social inclusion and the promotion of choice and independence. We have discussed all of these in other chapters.

## 7.3 Needs

### Numbers of disabled people

It has been estimated that the prevalence of disability is 14% for people aged 16-65. Put another way, there are at least 7 million disabled people in the UK, many of whom receive support from the NHS or local authorities (Audit Commission 2000).

Data from the British Household Panel Survey were analysed by Burchardt (2000) to explore the 'dynamics of being disabled'. She found that only a small proportion of those people of working age who experience disability are actually long-term disabled, even though at any one time it was found that long-term disabled people make up a high proportion of all disabled people. In Britain, in any particular year, approximately one person in ten of working age is limited in their daily activities, of whom three-quarters are on long disability trajectories. Over a seven-year period, however, as many as one in four people experience some limitation, of whom only 10% are disabled throughout. More women than men of working age experience disability (Burchardt 2000), although men who become limited in their activities of daily living are slightly more likely to remain disabled for a longer period. Older people of both sexes are more likely than young people to become disabled.

Some information on people with sensory impairments in England can be provided in graph form. From figure 7.1 it can be seen that there has been a steady rise in the number of people registered as sensory disabled between 1980 and 2001. This increase is most notable in the numbers of people who are hard of hearing and those who are partially sighted. These changes may be due to the ageing of the population, or a growing willingness to register as sensory disabled.

Figure 7.2 shows that the percentage of people registered as blind between the ages of 18 and 49 has decreased since 1982. The great majority of people registered blind are over age 65; the proportion grew steadily between 1982 and 1997, when it began to stabilise (figure 7.3). As seen from figure 7.4, the great majority of people registered as partially sighted are, again, over age 65; this proportion grew steadily between 1982 and 2003.

Figure 7.5 summarises similar data for Wales. It shows that the number of people on the Welsh register of sensory disabled persons, including those who are blind, deaf with or without speech, and those who are hard of hearing, rose between 1980 and 2001. Again this could reflect population ageing or increased willingness to register as sensory disabled.

There is a small amount of information on people in Northern Ireland. Figure 7.6 suggests that there has been little change in the number of people who are hard of hearing who have had contact with providers since 1998. Figure 7.7 shows similar information for people who are deaf and without speech; there has been a drop in the numbers who have had contact with providers since 1998, most notable in younger age groups.

## Differing needs of disabled people

The Department of Health position is that the needs of disabled people should be seen as spanning at least the dimensions of accommodation, finance, education, employment, leisure, transport and access, as well as the personal, social and health care needs that are the primary concern of this chapter. It does not make sense to maintain rigid distinctions between these dimensions, for the development of a new need in one area (or the failure of services to meet existing need) can obviously have major implications in other areas of an individual's life. Some commentators have sought to identify priority areas of need: for example, Swain (1993) listed somewhere to live, appropriate care services, mobility, access and opportunity. 'The lack of housing', he argues, 'is lamentable' (p.990). And, of course, over time it has been increasingly recognised in policy and related discussions that disabled people should be included at

the earliest stages of needs identification, service consultation and planning; that is, to be given full opportunities to take control of the services that meet their needs. We return to this topic later in the chapter.

There is plenty of evidence from the literature that we were able to locate that these needs are often not being met. One study of the needs reported by severely disabled people (excluding those with hearing or visual disabilities) found that 89% of participants reported at least one unmet need (Kersten *et al* 2000). Such unmet needs mostly related to practical matters, such as adaptations, equipment and physiotherapy, rather than needs for intellectual or social fulfilment. Even those people who were in touch with community rehabilitation services continued to report or express unmet needs for further services. No relationship was found between level of disability and unmet need (Kersten *et al.* 2000). An earlier survey by Mulcahy *et al.* (1993) had noted a considerable disparity in levels of unmet need among disabled people whose sole regular contact was with health professionals, compared with those reassessed on a multidisciplinary basis by health and social services personnel.

The *Fully Equipped* review by the Audit Commission (2002) found that people responsible for commissioning and providing equipment services had little idea of underlying demand, and again documented widespread unmet need, resulting in the exclusion of disabled people in many other life domains.

Another study found that most disabled people with modest needs were able to satisfy their requirements for themselves, reporting that they gained very little from interventions by nurses, occupational therapists or social workers. Many needed only minimal help to continue to live independently. They sought good advice and opportunities to try out equipment. Early intervention was important, however, to sustain self-confidence and a sense of independence. Clark's (2003) report for the SSI noted that most disabled people want to live independently. The requirements to achieve this were set out, and we can quote her list verbatim:

- easily accessible public information about services and who is eligible for them;
- convenient and consumer-friendly ways to make referrals and receive services;
- timely, person-centred assessment and care planning that actively involves service users and carers and promotes independence;
- reliable, well informed and accessible care managers who ensure that people are treated with dignity and that their culture is respected;
- a rights-based approach to active citizenship, including opportunities for work, leisure and being a parent;

- access to direct payments so as to maximise individual choice and flexibility;
- reliable, timely, flexible and high quality provision;
- a range of services to meet specialist needs relating to physical disability and sensory impairment;
- speedy responses to housing needs;
- rehabilitation which actively promotes independence and reduces dependency;
- safeguards against abuse and poor treatment;
- carers' assessments and responsive services to meet carers' needs;
- active participation in developing services and appraising quality;
- clearly understood and responsive ways to register comments and complaints;
- fair charging arrangements and advice on maximising benefits; and
- seamless connections between agencies and in particular with education, health and housing.

'Culturally sensitive local services for black and minority ethnic disabled people are not well developed' (Clark 2003, p.5). Deaf-blind people and people with acquired brain injury and other complex needs are also not well served: their needs are not identified or met. Inappropriate and sometimes remote placements may result.

Most authorities were reported as having revised their social care eligibility criteria according to the *Fair Access to Care Services* guidance (Clark 2003). There was a strong commitment to the social model of disability.

## The needs of people who have had a stroke

Stroke is the most common cause of disability in the UK. It can affect people of all ages: projections for 2001 showed that 21% of all new strokes occur in people under age 65. A recent study found that people who had experienced a stroke reported many unmet needs. This was particularly common among those with poor mobility, who tended to need help with their mobility (both at home and elsewhere) as well as more therapy, and advice on and provision of respite arrangements and day care. Those who were unable to return to work had more unmet needs and experienced difficulties with their finances.

Younger people (under age 65) reported more unmet needs related to intellectual fulfilment, help with family issues and holidays, and continued to report needs several years later. There were no differences in unmet needs by socio-economic background. Most of the expressed needs of the participants were, in fact, for services generally available, suggesting that there are problems in the sufficiency of resources and their distribution, rather than in the kinds of services on offer (Kersten *et al* 2002).

## People who have experienced an injury

Injuries are a key cause of mortality and morbidity in young adults. Many people suffer serious non-fatal injury, resulting in some 720,000 hospital admissions each year (Department of Health 1998) and more than 6 million attendances at A&E (Ward and Christie 2000). The cost to the NHS of treating traumatic injury is around £1.2 billion per annum, some 7% of its annual budget (Department of Health, 1996). The true economic cost to the nation is undoubtedly higher, as many of those injured suffer permanent disability, limiting their ability to work (Evans *et al* 2003).

A key issue is the long lasting nature of disability for many people. One study followed up the survivors of serious injury after five years in one region, finding that 81% had some form of measurable disability (Airey *et al* 2001). Evans *et al* (2003) interviewed the young people involved (aged 11-24 years at the time of injury). Although many had no disability, or experienced little or no impact on their daily lives as a result of their disability (possibly because they were still living with their parents), a number reported considerable limitations, particularly with respect to work. Almost half of those who were no longer in full-time education were without a job; of these, one third stated that their disability made it impossible for them to work, with many feeling that they could be helped by greater availability of sheltered or part-time employment. Half of those interviewed stated that they would have liked additional help to cope with their injury or disability.

## Carers

Increasing attention has been paid to the needs of carers. The Carers (Services and Recognition) Act 1995 provided carers with a statutory right to an assessment of their needs. More recently, carers were given the right to expect the NHS and social services to help to maintain their general physical and mental health, often put at risk by the burden of caring (Department of Health 1999). In 1999, the Government introduced new grants and paid local authorities an extra £140 million over three years to enable them to provide a wider range of respite services (Department of Health 2000). Few carers have received a separate assessment and few local authorities inspected by the SSI had a carers' strategy (Clark 2003).

As we saw in chapter 6, families with disabled children very often face additional expenses associated with the needs of their children, accompanied by reduced income. They may need practical help, such as aids and adaptations, as well as information about relevant services and how to gain access to them. Some may need other forms of support. Despite these needs, some research suggests that families of disabled children tend to have little help; for example, one study of families of children with a hidden disability (bowel impairments) found that families tended to have limited social work input (Cavet 2000). Most reported no contact, a smaller group reported a very low level of contact, generally concerning financial issues, while a very small number had come to know a social worker well during a period of difficulty. Among the first group, some had not wanted any contact, due to lack of trust in social workers or because they doubted their ability to help. Yet they had many unmet needs for help, particularly information about available services. We discussed the evidence on disabled children in chapter 6 and do not go over that same ground.

## 7.4 Funding

As is the case for other social care areas, support for people with disabilities is provided in an increasingly mixed economy. As well as local authority social care and NHS funding, the voluntary sector has a long history of being quite a major funder and provider (Kendall 2003). The benefits system – which we do not discuss in this chapter – also obviously plays a major role.

### Local authority expenditure on disabled people

In England, expenditure by social services on home care for physically disabled adults under age 65 increased from 1994/95 to 2002/03 in line with policy intentions, although expenditure on nursing home placements also grew over the same period (from 4% to 12%). Direct payments accounted for 6% of this expenditure in 2002/03 (not available in 1994/95). Assessment and care management expenditure decreased by 2%. This information is illustrated by comparing figures 7.8 and 7.9.

Indeed, as shown in figure 7.10, gross expenditure on social services for this group has grown faster than inflation since 1994/95. Expenditure on residential care home placements grew consistently between 1994 and 2003. 'Other non-residential costs' has been re-defined since 1999/2000 and now encompasses services such as meals, equipment and adaptations. It can be seen from figure 7.11 that the average costs of residential and nursing care for adults with physical disabilities in England have grown faster than inflation since 1998. The smallest growth in average costs (but still quite substantial) was observed in the metropolitan districts.

Data for Wales are shown separately: total expenditure on social services for physically disabled people increased above the level of inflation between 1997 and 2003 (figure 7.12). Purchasing costs (that is transaction costs) have risen slightly, as have residential care costs. Net expenditure on physically disabled people has grown, both in total and as a percentage of total expenditure for all client groups since 1997, as can be seen from figure 7.13.

Evandrou and Falkingham (1997) note that inflation-adjusted expenditure on social care for younger adults with physical disabilities grew by 9.3% per annum between 1986/87 and 1994/95, faster than expenditure on children, older people or people with learning disabilities. However, they also note that, 'although there have been marked improvements in the provision of domiciliary care and other support services, ... they have been struggling to keep pace with changes in need' (p.232).

## The Independent Living Fund

As noted above, the Independent Living Fund (ILF) was established in 1988 as an independent trust to provide resources for severely disabled people who needed help with domestic and personal care in their home. Although there were income criteria for eligibility, exceptional payments could be offered to prevent people entering institutional care. Successful applicants received cash directly into their bank account or that of a carer.

The initial budget of the ILF was £15 million, but by 1993 it had increased to £97 million, with around 22,000 people receiving funding. Two new trusts have been established, one with a budget of £117 million to provide continuing payments to those already receiving ILF funding, and one with an initial budget of £4 million for new awards to around 1500 severely disabled people of working age each year (Doyle, 1995).

## Direct payments

Although many different groups are in principle eligible to use direct payments, the greatest use is made by disabled people: in 2002, they represented almost 70% of all people receiving direct payments (Clark 2003). Yet the numbers are only a small proportion of all disabled people (1.8 per 10,000) and there are very marked local variations (Audit Commission 2002; SSI and Audit Commission 2004). There are also variations *within* the population of disabled people, for instance by type of disability (for example, those with sensory impairment are under-represented). 'Poorly performing authorities need to strengthen arrangements to promote the take-up of direct payments and provide more effective and positive support for users to manage and take control of their own care arrangements' (SSI and Audit Commission 2004 p.29). The SSI report of

inspections and information collections recognised that 'staff need training in the ideas behind and the practical workings of direct payments' (Clark 2003 p.7).

The Government has continued to promote direct payments. In September 2003 guidance was issued requiring councils to offer an arrangement for direct payments to any eligible person who wants one. In August 2003, the first local authorities awarded funding under the Direct Payments Development Fund were announced. In 2004, the provision of direct payments became a central performance indicator to be taken into account when councils are awarded their star rating.

## Housing and adaptation costs

A study in the early 1990s noted the high burden of costs for adaptations and aids for younger physically disabled people and their families (Hull *et al.* 1994). The authors argued that it might actually be cheaper in the long run to meet the housing costs of disabled people, rather than to fail to meet them. The Housing Act 1989 was said to have some anomalous effects: although enabling housing associations to provide more purpose-built housing for disabled people, this was relatively expensive and they might not wish to incur the extra expense. Moreover, adapted public accommodation was diminishing as a result of council house sales and reduced building; constraints were thought to be likely to make local authorities reluctant to give grants for private rented housing, and also give less security of tenure (Hull *et al.*, 1994).

At present, local authorities with housing responsibilities can pay Disabled Facilities Grants to fund adaptations, such as wheelchair accessible showers, for disabled people in owner-occupied or private sector rented accommodation to enable them to live more safely and independently. Yet there are very long waiting times for home adaptations: the average wait between initial assessment and the commencement of work was 33 months in 2002 in England. There is a shortage of occupational therapists (Clark 2003).

## User charges

In October 2002, local authorities in England began implementing the Government's guidance on charging for care services, *Fairer charging for home care and other non-residential social services* (Department of Health 2001, 2002). To check how the new guidance was affecting the lives of disabled people, service users were invited to take part in a survey. It was found that despite national guidance, there were some inconsistencies with charging policies, with a majority of service users and carers finding it difficult to get information on the policies of their local authority. Moreover, charging for essential services continued to have a negative impact on people's personal finances and lifestyles. A number found that they had to stop or cut back on

the services they needed. Although most did not find that charging policies acted as a barrier to gaining employment, some were deterred from seeking employment, because of a fear that it would affect the services received.

## Supporting People

The Supporting People programme, funded from April 2003 by the Supporting People Grant, aims to encourage the independence of vulnerable people through housing-related support in the community. Although a few inspected councils were progressing well in developing local housing plans, the needs of disabled individuals were generally found to be of low priority (Clark 2003).

## 7.5 Resource inputs

The dramatic changes over the past 15 years or so in the relative provision of hospital and various forms of community care have been recounted in other chapters and do not need to be repeated here. Nonetheless, they also had enormous consequences for disabled people under age 65. Convalescence and rehabilitation now tends to occur in private nursing homes or domiciliary settings, rather than in hospital. Rummery and Glendinning (1999) argue that a cumulative consequence has been the shift away from universal access to NHS provision towards 'residual' local authority provision. Many disabled people are receiving domiciliary home help and day care services, increasingly subject to means-tested charges.

One example of the potential to enable home care for severely disabled people is illustrated by research on people with spinal injuries who need ventilators. Based on work by the Southport Spinal Injuries Centre, Bingley (1993) examined the real cost of helping such people to live at home and made an economic case for such a policy (Bingley 1993).

Clark (2003) noted that home care services were facing recruitment difficulties for skilled staff.

We have surprisingly found only limited research on family members, spouses or others caring for younger disabled people. Studies of people with multiple sclerosis suggest that where carers have a poor quality of life, the disabled person is at greater risk of depression (Aronson 1997). Studies of carers of people with rheumatoid arthritis have identified high levels of burden and psychological distress (das Chagas Medeiros *et al.* 2000). A study of carers of people with reflex sympathetic dystrophy (RSD, a neuropathic pain syndrome following surgery or trauma) found that half were suffering

significant levels of strain, low mood and poor adjustment, but there was no significant relationship between strain and level of carer support.

## 7.6 SERVICES

### A general overview

We have already drawn quite extensively on the review of the performance of social care services for physically and sensory disabled people that consolidated information gathered by the Social Services Inspectorate from inspections and monitoring data during 2002/03 (Clark 2003). This review concluded that services had improved in the following ways:

- 'the number of disabled people receiving help to live at home has increased steadily;
- more people are receiving direct payments and are enthusiastic about how these have improved their quality of life;
- most councils are making progress on integrating community equipment services with health partners;
- deaf people and blind people receiving specialist services, often from voluntary organisations, expressed high levels of satisfaction;
- councils are starting to develop community-based alternatives to traditional day services;
- Welfare to Work strategies are expanding employment opportunities, especially when all relevant council departments take responsibility for making progress;
- most councils have adopted the social model of disability, although they need to audit its effectiveness in practice; and
- service users and carers were becoming more involved in planning and developing services' (Clark 2003 p.4).

This report also noted some key areas for development. It was proposed that home care should be more flexible and reliable and that greater attention should be given to promoting independence when home care services were commissioned. Furthermore,

more disabled people should receive direct payments and expectations regarding the range and quality of the services should be raised.

The summary account of the joint reviews by SSI and Audit Commission (2004) was also critical of the quality of practice: 'For younger people with physical disabilities there remains an even bigger challenge [than for people with learning disabilities] and a pressing need for a national framework to drive improvement. Good practice for this user group has not been easy to find' (p.29).

Returning to the 2003 SSI review, the report reflected that

Councils organise and plan services for disabled people in a variety of ways. The common factors that help to produce quality services and satisfied service users include:

- joint commissioning and service strategies along with explicit budgets for services for disabled people;
- effective links between social services, health and other services and independent providers;
- the involvement of disabled people in strategic planning and specific initiatives;
- a dedicated adult disability team and a lead manager or other 'champion' for disabled people; and
- ongoing and specialist staff training and development (Clark 2003 p.7).

## Recent trends

In England, the number of adults with physical disabilities helped to live at home increased across the country between 1998 and 2003, with the exception of London, as shown by figure 7.14. The data summarised in figure 7.15 show that the number of physically disabled people estimated to be receiving community-based services increased between 2001/02 and 2002/03. The number of frail people receiving community-based services also grew slightly. Figures 7.16 and 7.17 show the services that are the most commonly used by physically disabled people. Noticeable are the levels and trends in use of equipment and adaptations, professional support, home care and meals. It may be worth noting that fewer people used almost all community-based services in 2002/03 than in 2001/02. This may have been a result of the more intensive targeting of services, as with older people.

Conversely, the number of admissions of people with physical disabilities to various forms of accommodation fell over a similar period, as shown by figure 7.18. Permanent admissions to all types of accommodation fell between 1997 and 2003; temporary admissions grew between 1997 and 1999, but by 2003 had fallen to below their level at the start of the period. Despite these trends, the number of disabled people in independent residential care homes increased, but those in council staffed accommodation fell (see also figure 7.19); the numbers in independent nursing homes remained the same. Altogether, there has been a drop in the number of places in residential care homes for physically disabled adults between 1994 and 2001, particularly local authority homes, as shown by figure 7.20. The number of homes grew from 1994 to 1997 but has since fallen (figure 7.21).

Over an earlier period, Evandrou and Falkingham (1997) reported the decline in local authority residential care provision from over 10000 residents in 1977 to 6500 by 1990 and 7200 by 1995 (equivalent to a 2% annual drop when averaged over the period). The overall volume of residential provision also fell over this period, from over 11,000 residents in 1974 to just over 7000 in 1995. Over a slightly shorter period local authority day places for people with physical and/or sensory disabilities fell slightly from 10300 in 1977 to 9200 in 1992. In both cases there was steady growth in the volume of contracted-out provision. Indeed, looking at the Department of Health figures reported by Evandrou and Falkingham, residential care market shares changed in many ways over the period 1974 to 1995. Local authority-funded provision fell in volume, but within the total there was a shift away from in-house services towards voluntary and private services, the latter growing especially fast from a very low base after 1993. There was also quite steady growth in non-local authority-funded provision in the voluntary and private sectors during the 1980s (presumably mainly funded by DSS and probably linked to the rundown of long-stay hospital provision). Immediately after implementation of the 1990 Act there was a clear switching of private sector residential care services from non-local authority to local authority funding, but apparently not for voluntary sector provision.

The period that physically disabled people must wait for an assessment appears to have lengthened in 2002/03, compared to 2001/2. Figure 7.22 shows that the modal period from first contact to completed assessment for physically disabled people in England in 2003 between two and six weeks. Unacceptably long waits between assessment and receipt of services were common (Clark 2003). The SSI summary report recommended that assessment and care management should be 'more person-centred and holistic, with more priority given to self-assessment, risk management and regular reviews' (Clark 2003 p.7).

Councils' performance has improved: in 1998, 51% of councils were rated 3\*, whereas this figure had risen to 70% in 2003.

Information on service provision in Wales can also be presented. Unlike in England, the number of places in local authority homes for physically disabled people grew steadily between 1980 and 1995, but stabilised after 1997, as shown in figure 7.23, with the vacancy rate also growing since 1980. The number of places and number of residents in private and voluntary homes has fallen considerably between 1980 and 2001. The combination of a rise in the number of homes (all sectors) over the past two decades, together with a fall or stabilisation in the number of places, suggests that average home size has fallen.

Figure 7.24 shows that the number of assessments and non-residential 'care packages' for people with sensory or physical disability in Wales increased between 1994 and 2001. The number of vehicle badges issued to physically disabled people rose between 1987 and 2001, as shown in figure 7.25.

In Northern Ireland there has been an overall increase in the number of people offered social services help between 1998 and 2003 (figure 7.26); the private sector has grown more than other sectors, particularly with regard to nursing home care. The number of physically disabled people receiving home help services has increased since 1998, as can be seen in figure 7.27. There was a drop in the average available places in voluntary sector residential accommodation between 1998 and 2003 (figure 7.28), while the average available places in the private sector almost doubled. We earlier described the numbers of people in Northern Ireland with hearing problems who were in contact with services (figures 7.6 and 7.7).

Figure 7.6 suggests that there has been little change in the number of people who are hard of hearing who have had contact with providers since 1998. Figure 7.7 provides similar information for people who are deaf and without speech; there has been a drop in the numbers who have had contact with providers since 1998, particularly in younger age groups.

## Equipment services

Equipment services are fundamentally important to many disabled people: they provide self-sufficiency, independence, dignity and self-esteem to disabled people. It has been estimated that roughly 4 million people receive some help with equipment provided by the NHS or local authorities. *Fully Equipped*, the report of a substantial enquiry by the Audit Commission (2000), updated two years later (Audit Commission 2002), looked at five equipment services: orthotics, prosthetics, wheelchair services, community equipment and audiology. The report showed that the organisation of equipment services was very inefficient. Many services were small and poorly managed and users were not always provided with equipment of a suitable standard. The pivotal importance of this is clear:

Equipment for older or disabled people provided the gateway to their independence, dignity and self-esteem. It is central to effective rehabilitation; it improves quality of life; it enhances their life chances through education and employment; and it reduces morbidity at costs that are very low compared to other forms of health care. It is no exaggeration to say that these services have the potential to make or break the quality of life for many older or disabled people, and of the 1.7 million people who provide informal care for more than 20 hours per week (Audit Commission 2000 p.6).

The Audit Commission (2000) report recommended action in a number of areas. There should be greater integration and joint action between health and local government (such as joint equipment stores). The profile of equipment services should be raised by the Department of Health, and there should be better clinical leadership. On quality, the Commission urged a review of waiting times for the provision of equipment and the clarification of eligibility criteria. It was also recommended that attention should be paid to the acquisition costs of equipment and the possibilities of recycling equipment. The Audit Commission's study in a range of localities found that services for the most part are bedevilled by:

- lack of involvement of users at all levels of service planning and delivery;
- low priority afforded by senior managers to equipment services;
- under-investment by the public services and the supporting industry, and
- geographic variations in people's eligibility to receive services, in the range and quantities of treatment provided, the time spent waiting for its delivery, and in the number of staff trained and the intensity of the education and training that they receive (Audit Commission 2000 p.85).

The 2000 report from the Audit Commission attracted a lot of attention, but generated little change. The Commission's own report two years later reflected frankly that it had 'been of limited value to users of equipment services' (Audit Commission 2002 p.48). Encouraging signs of progress were to be found, but the overall impression was disappointing. Policy recommendations were to 'Promote independence as a means of delivering important health care and social priorities: promoting social inclusion; relieving pressure on acute hospitals; and complying with the Disability Discrimination Act' (Audit Commission 2002 p.51). The NHS and social care *Planning and Priorities Framework 2003-2006* set a target that by December 2004, all community equipment should be provided within seven working days.

The NHS Plan included an intention to achieve a single, integrated community equipment service by April 2004. Guidance on the integration of community equipment services was issued to the NHS and local councils in March 2001. It set ambitious targets to increase by 50% the number of people benefiting from these services and to

improve the quality of the equipment issued. The Department of Health established a national implementation team to help trusts and social services implement the guidance by the target date, including additional funding for community equipment services, as follows:

2001/2	£12 million
2002/3	£28 million
2003/4	£65 million

**Total** **£105 million**

An extra government grant was also promised to local authorities in their personal social services settlement for 2001/02 to 2003/04, so that they too could support government policy. The Health Minister said that in total 'over £200 million' across the NHS and local government had been made available. However, it has been suggested that little of the first year funding actually reached frontline services.

Similar problems were experienced in Wales in implementing the Audit Commission's recommendations, primarily because of a lack of dedicated funding and, in some areas, a history of poor relations between local social services departments and NHS trusts. In 2001/02, £2.25 million was spent on improving the infrastructure and ensuring that all audiology departments could offer new technology hearing aids by the end of 2002. A further £1.7 million was allocated to health authorities in 2002, primarily for them to purchase new technology hearing aids for the following year.

A stock take of the position in 2002 showed that progress in improving these services was patchy; there were good developments in audiology and in community equipment services, but less progress in mobility services. These differences may have been linked to the targeting of additional funding.

The priorities and planning framework and health authority revenue resource limits for 2002/03 contained three inter-related priorities: improving emergency services, reducing waiting times and increasing capacity. Equipment services were argued to have a major role to play in delivering all of these objectives.

## Services for blind or partially sighted people

Several reports have been produced on services for blind or partially sighted people. Taken together, they paint a picture of extensive and deep-seated poverty, significant care needs that are not being met, and widespread social isolation.

The key messages are that approximately 1.7 million people in the UK could be categorised as being blind or partially sighted. Ninety per cent of people with a serious sight problem are over age 60 years and these are more likely to live alone, suffer restrictions in everyday life, and have other age-related conditions, such as hearing loss, and physical limitations. Three quarters of these people state that they need help with the activities of daily living. One quarter have never received a visit from social services. A lack of adequate transport means that many become housebound and 60% never go out alone. Low incomes are common: 90% of the group had income of less than half the national average. Ten per cent were aware that they could claim benefits but did not, either because they could not fill out the forms or they did not have the information about how to claim. Comorbid problems were also common: three quarters are living with other health needs or disabilities (Audit Commission 2002).

## Community care

Providing care in the community is of course the foundation of current health and social service policy (Department of Health 1990). For disabled people, such care consists of medical, personal and domestic services and may be provided by formal sources, such as district nurses, local authority home helps, private agency carers and people from voluntary organisations or by family and other carers. The latter may claim invalid care allowance if they are unemployed and provide more than 35 hours of care per week.

The SSI review of progress, through position statements and inspections, found that 'most home care services remain task-focused, placing service users in a passive "done to" role rather than enabling them to control their own support package and change it as their needs change. Particularly in the independent sector, home care services are not reliable or flexible enough' (Clark 2003 p.5).

The review also concluded that local authority day services were beginning to be reshaped, with the move away 'from traditional centre-based services to outreach and community-based day activities... Not all services users welcome such changes and a range of day services needs to be retained in the short term' (Clark 2003 p.6). Advocacy services are valued by users but not very widely provided. When there was a local corporate commitment to implementation of Welfare to Work, more jobs were created for disabled people.

A study of a sample of people receiving help from the Independent Living Fund provides insightful data on the nature of the care services received by poor, severely disabled people living in the community (Phillips 1995). Over half of the Fund's beneficiaries were aged 60 or over and over 20% lived alone. This group received a mean of 71 hours a week of care, from both formal and informal sources, of which only 7% came

from health or local authorities. Over half the sample (53%) received no care from formal sources. As we saw earlier there is considerable unmet need for community-based support services in the disabled population.

## Satisfaction with services

As noted in other chapters, and as we discuss further in chapter 9, we do have some reservations about the interpretation of data on service user satisfaction. The SSI summary review found that service users' satisfaction levels were generally good, but added the rider that expectations of social care services were low (Clark 2003).

## Choice and services

Service users and carers are becoming more involved in the planning and development of services, but the overall impression from SSI evidence was of constrained opportunities, insufficient support to allow people to live independently, and experience of home care services that actually promoted dependency (Clark 2003). Involvement should, however, enable disabled people to develop services to meet their needs, providing more choice of appropriate services in the future. However, the summary of SSI inspections and reports also noted the difficulties that disabled people and carers encounter in tracking down 'information about services in appropriate formats and languages' (p.6). Communication preferences need to be better understood. Service user involvement in 'commissioning, planning and developing community-based disability services' remained limited. Where strategic-level engagement was established, frontline services were more responsive to users' needs and preferences (Clark 2003 p.7). As we noted earlier, the take-up of direct payments has been growing but still quite slowly.