

REPORT

22 June 2005

Developing social care: the current position



Chapter 8: People with learning disabilities

8.1 Terminology and process

Throughout this chapter we use the term *learning disability*, unless when directly quoting others who use alternative terms. We are, of course, aware that other terms are being used increasingly today, particularly *intellectual disability* and *learning difficulty*. A person with a learning disability is sometimes now described as a person *labelled* with a learning disability. Challenging behaviour is another term now sometimes dropped in favour of *high support needs*, although the latter also has broader meaning. We have chosen to use the terms *people with learning disabilities* and *challenging behaviour* throughout to be consistent with the language employed by SCIE and the Department of Health.

We are also adopting a standard definition of learning disabilities of the kind set out by Emerson et al (2001): learning or intellectual disabilities include ‘the presence of a significant intellectual impairment and deficits in social functioning or adaptive behaviour (basic everyday skills) which are present from childhood’ (p.5). As with most UK studies we will distinguish between mild and severe disability, although some of the more clinical literature uses terminology and categories taken from ICD-10: mild, moderate, severe, and profound ‘mental retardation’.

A second prefatory remark concerns the process of writing this chapter. We have faced time constraints in completing this project for SCIE because of the considerable volume of evidence that we have needed to locate, retrieve, interpret and summarise in logical fashion. In some social care areas, and particularly in relation to learning disabilities, the coverage and quality of routinely available data are poor. As the 2001 White Paper, *Valuing People*, itself noted: ‘National data on learning disability issues are currently underdeveloped’ (Secretary of State for Health 2001 p.114). The White Paper went on to announce a project to improve the Department of Health’s own data collection. The Department has also recently had to commission a special study to collate data in order to assess whether the objectives of the White Paper have been attained. Difficulties of this kind have restricted the amount of time available for the later chapters in this report (on people with physical and learning disabilities). They also make it difficult to draw conclusions on some trends.

Finally, we should note that some documents have proved to be very useful in preparing this chapter. The first is now more than three years old. It is an overview of learning disabilities published by the Foundation for People with Learning Disabilities, written by Eric Emerson, Chris Hatton, David Felce and Glynis Murphy (2001). The second is the 2001 White Paper *Valuing People*, which is much richer in content than most white papers. Although as just mentioned it is not possible with existing data to tell whether all

of the central aims of the White Paper have been achieved, the policy document appears to have been well received. The *Valuing People* website is also helpful. Third, we found the Department of Health's two annual reports on learning disability services to be informative if general reflections on achievements (for 2003 and 2004), as were the annual reports from the Learning Disability Task Force. The summary of nine SSI inspections in 2001 gives the most recent account of local developments and challenges (Cope 2003).

8.2 Policy context

The 1990 legislation

The concerns and considerations that led to the 1989 community care White Paper and the 1990 legislation have been well rehearsed already in other chapters. There are numerous specific accounts of the issues for learning disability services; those with which we are particularly familiar are Hardy et al (1990), Renshaw et al (1998), Knapp et al (1992) and Cambridge et al (1994). This is a somewhat biased sample, and there are many other such accounts.

The period preceding the 1989 White Paper saw many changes.

The period of the late 1950s through to the late 1980s was exciting and significant in many respects, not only for the dramatic changes in philosophies, attitudes, and social policy developments that impinged on the lives of all people with disabilities, including those with intellectual disability, but also for the rich array of applied research that sought to discover new knowledge to inform both policies and practices (Parmenter 1999).

The 1990 Act offered a new framework and a refocused set of objectives to take community care forward. At the core of the 1989 White Paper and 1990 legislation – and looking across all service user groups – was a re-statement of the Conservative government's commitment to care in the community, especially in ordinary domiciliary settings with appropriate peripatetic support, in preference to long-stay residence in hospital, residential care homes or nursing homes. For people with learning disabilities, the emphasis on ordinary accommodation (supported housing) was relatively muted in the early 1990s, and has become a much more influential policy objective only relatively recently.

Supply pluralism was strongly encouraged. A mixed economy of provision was already developing for learning disability services in many localities, and the 1990 Act clarified the lead role to be taken by local authorities as enabling agents. More generally, there

was some clarification and realignment of the balance of responsibilities between the NHS, central government's social security roles and local government. Some of the funding that would previously have been routed through social security payments would be transferred eventually to local authority social services departments. The major public sector actors in each locality were required to agree an annual plan for community care in consultation with the voluntary and private sectors, service users and carers. And of course, a fundamental commitment was to needs-based planning, preferably co-ordinated through case or care management. In relation to the last of these, learning disability practice in some locales had already introduced individual service planning or person-centred planning.

Many of the elements of the 1990 central policy framework were therefore fairly widely accepted or established as parts of existing local practice for people with learning disabilities. Most obviously, the emphasis on closing long-stay hospital provision and replacing it with suitably supportive facilities in the community had been given emphasis at least since the 1971 White Paper, *Better Services for the Mentally Handicapped*.

Developments over the 1990s

Although many of the aims set out in 1990 were therefore broadly welcomed, there were a number of concerns. One was that health and social care roles were still separated, when the needs of individuals with learning disabilities 'seem inextricably intertwined' (Mansell 1994 p.298). Ironically, as Hudson (2003) later commented:

Despite seeming to represent the epitome of good partnership working in the 1980s, service systems concerned with learning disability now seem unduly fragmented. Amongst the reasons put forward in the [2001] White Paper to explain this situation are a lack of agreement about values and service objectives, an inability or unwillingness to agree on financial arrangements, and the low priority being given to joint working within organisations. This general fragmentation can be expected to be even greater at times of transition, where there is a transfer between service systems, as occurs in the case of the move from adolescence to young adulthood (Hudson 2003 p.263).

Another concern, discussed by Mansell (1994) among others, was that the laissez-faire approach to local policy and practice, with central government reluctant to be too mandatory, did not give sufficient impetus to close down the remaining hospitals. There was also the financial hurdle. The Audit Commission (1992) reported how average cost per inpatient place for people with learning disabilities grew by 60 per cent between 1979 and 1989 while total expenditure fell marginally and the number of inpatient places fell by 40 per cent. These trends would have continued into the 1990s. Clearly the full

financial implications of the resettlement of long-stay hospital residents was taking time to work their way through, and at the same time it was the people with the highest support needs (including those with mental health problems, challenging behaviour and multiple disabilities) who were likely to remain in hospital beds, as it was harder and more costly to develop alternative places of accommodation for them. The Audit Commission (1992) stressed the importance of arrangements to transfer money from hospital to community-based services in order to ensure good quality of care. The challenge for health authorities was that they were being asked to transfer money from hospital to community-based services, including funding social services activities, at a time when their access to social security funds to support people in residential and nursing homes was being cut off.

As Mansell (1994a) wrote:

English government policy, although favouring the development of community-based services as alternatives to institutional care since the scandals of the 1960s and 1970s, has remained equivocal about the future role of institutions for people with multiple disabilities or with behaviour problems. Despite the development of model services that did serve these people, first in larger community-based facilities and then in group homes, there is evidence that, as in American studies, people with behaviour problems are less likely to be offered community services until the end of the de-institutionalisation process. These people are also more likely to be re-institutionalised, and there is some evidence that English community services, where they are set up with emphasis on normalisation ideology rather than how to realise this in practice, may have particular problems serving people with problem behaviour. How best to serve people with problem behaviour therefore represents perhaps the most important challenge to community services in England at the present time (pp.371-372).

There were also still many, loud and quite influential voices arguing for retention of a hospital model, although often transmogrified into village or intentional communities. It was a few years before a Department of Health-funded evaluation mapped the relative advantages and disadvantages of village communities, NHS campuses and dispersed housing models in the community (as we discuss later).

A further concern in the immediate aftermath of the 1990 Act was that

some health authorities appear to have misunderstood the community care reforms to mean that they would have no continuing role in the care of people with learning disabilities beyond what they provided in general and psychiatry hospitals, and that as a result no further investment (perhaps even asset-

stripping) was taking place in health authority learning disabilities services (Mansell 1994 p.299).

The Department of Health had quickly to issue guidance to dispel such notions. The Department of Health also set up a project group, chaired by Jim Mansell, to look at four specific local service approaches for people with challenging behaviour or mental health needs, and to make recommendations for the wider development of local learning disability services. Mansell (1994) himself provides a very helpful summary of the report's main themes, organised under five heads: the social context of challenging behaviour; the importance of management commitment; the service development process; empiricism and cost constraints; and comprehensiveness. The full report was published by the Department of Health (1993). The Mansell Report provided the necessary post-1990 Act detail to guide a number of learning disability service development during the 1990s. It offers useful reflections on, and guidance in relation to many of the topics tackled in this chapter, including:

- the individualisation of services,
- their targeting on needs and the problem of gaps,
- the weakness of management commitment as a major barrier to service improvement,
- reluctance in a number of areas to develop local services or only to seek cheap versions of institutional care,
- continuing problems of and on the boundary between health and social care responsibilities,
- the need for investment in staff training and recruitment,
- the need for better use of existing funding and the injection of additional resources to meet the high support needs of some individuals,
- reiteration that 'value for money' and therefore by extension 'best value' cannot be judged only by looking at costs but requires evidence on outcomes,
- the need to base local decisions on evidence about relative effectiveness and cost-effectiveness,
- the need for better integration of the different parts of the broader system for supporting people with learning disabilities, and

- the recommendation to develop joint commissioning.

The All Wales Strategy took learning disability services forward in many ways. We do not detail those policy developments here, although we will do so as we draw empirical evidence from Wales throughout this chapter. For reflections on policy and practice developments around the All Wales Strategy see, for example, Evans et al (1994), Felce et al (1998), Perry et al (1998), Todd et al (2000) and Felce (2001).

A study jointly conducted by the Social Services Inspectorate, NHS Executive and the Department of Health Social Care Group looked at social care and health services for people with learning disabilities in 24 English local authority areas in 1998/99. Its purpose was to examine how far the policies set out in the early 1990s had been achieved (Department of Health 2000a). Among the conclusions were the continuing predominance of congregate care (for both accommodation and day activities), poor access to regular respite care and to mainstream general and mental health services, low commitment to staff training, confusion about definitions of disability and eligibility for service, lack of sensitivity to the needs of black and minority ethnic service users, poor commissioning expertise, little success in making information accessible to service users, and under-developed systems for monitoring assessments, care planning, service quality or performance. On the other hand, specialist community learning disability teams were being successfully introduced, there was improvement in inter-agency working to prevent, detect and investigate abuse, there was growing involvement of service users and carers in shaping local strategies, joint commissioning processes had been introduced (but there was continuing confusion about agency responsibilities and funding), and there was good progress in the introduction of assessment and care management arrangements. The implications drawn at the end of the report laid the ground for the 2001 White Paper, calling for national policy guidance, hospital closure, reduction in the use of other congregate care settings, reduction too in out-of-area placements, better employment opportunities, improved information for service users and families, development of service standards and better regulation, and improvements in joint commissioning.

Valuing people

The White Paper, *Valuing People: A New Strategy for Learning Disability in the 21st Century*, identified people with learning disabilities as 'amongst the most vulnerable and socially excluded in our society'. It was frank in its identification of 'major problems', and not surprisingly the list of specific issues overlapped hugely with those identified by the Department of Health group the previous year. Those noted in the White Paper included poor co-ordination of services, poor planning for young people at the point of transition into adulthood, insufficient support for carers, limited choice or control for people with learning disabilities, unmet health care needs, limited choice over accommodation, day

activities being dominated by availability rather than tailored to needs, poor opportunities for paid employment, unmet needs particularly for people from BME communities, 'inconsistency' in expenditure and service delivery across the country, and few examples of successful health/social care partnerships, or partnerships involving people with disabilities and their carers.

From this base the White Paper set out a number of objectives in pursuit of four key principles:

- The first of the four key principles was *legal and civil rights*: 'People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary' (Secretary of State for Health 2001 p.23).
- The second principle was *independence*, consistent with a number of public policy areas across the government's modernisation agenda. 'While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided' (p.23).
- The third principle of *choice* was obviously consistent with wider Government objectives. The aim for people with learning disabilities was to enable them 'to have as much choice and control as possible over their lives and the services and support they receive' (p.4). (The White Paper also quoted the government's mantra: 'The role of public services is to facilitate choice, not frustrate it.') The White Paper argues that a person-centred approach is an essential part of delivering real changes.
- The fourth principle, *inclusion*, 'means enabling people with learning disabilities to do those ordinary things, make use of ordinary services and be fully included in the local community' (p.24).

In pursuit of these principles the White Paper sets out 11 objectives: maximising opportunities for disabled children, transition into adult life, enabling people to have more control over their own lives, supporting carers, good health, housing, fulfilling lives, moving into employment, quality, workforce training and planning, partnership working. There were also objectives to improve partnership working 'To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services (p.106).

Valuing People and the subsequent implementation guidance issued to the NHS and local authorities make it clear that a person-centred approach to planning should start with the individual and not with services, and should act as a mechanism for reflecting

the needs and preferences of individuals with learning disabilities in the fields of housing, education, employment and leisure. All options should be considered when the future needs of people with learning disabilities and their families are being explored (Department of Health 2001). Local authorities also have the wider and continuing duty of Best Value, requiring them to deliver services by the most economic, efficient and effective means available, publish annual Best Value Performance Plans and review all of their services every five years (see e.g. Audit Commission 2002). The White Paper therefore stressed that services for people with learning disabilities and challenging behaviour should be commissioned on an individualised basis and should seek to promote inclusive lifestyles.

A Learning Disability Development Fund was established from April 2002 of up to £50 million per year, with 60 per cent of it (the revenue element) to be generated with the release of funds as hospital facilities closed. A separate fund was set up to promote advocacy and information. To ensure that change happened, a Learning Disability Task Force and Implementation Support Team were established.

Developments since 2001

The Health and Social Care Act 2001 included the requirement that the Department of Health reported on learning disability each year. Two reports have subsequently been published, both written in an accessible style (Department of Health 2003e, 2004b).

The 2003 report noted 'ten big things that are better since *Valuing People* came out', including greater support for families with severely disabled children, the establishment of more advocacy groups, growth in the number of people with learning disabilities receiving direct payments, establishment of a helpline, plans to move all people living in long-stay hospitals out to other settings, establishment of a National Forum to give people with learning disabilities access to government, the continued work of the Learning Disability Task Force, work by the Learning and Skills Council to identify the needs of people with learning disabilities, more people with learning disabilities getting jobs, and 3000 staff registered on the Learning Disability Awards Framework to enable them to get qualifications.

The National Forum of People with Learning Disabilities came into being in June 2001 with the aim of giving people with learning disabilities a voice at national level.

Learning Disability Partnership Boards were established in each local area from October 2001, bringing together local authorities and the NHS. The Partnership Boards involve the statutory sector, voluntary organisations, local employers, people with learning disabilities and carers. Each Board was required to draw up a three-year plan. The Learning Disability Development Fund of £42.6 million is partly under the control of

these Partnership Boards. Roughly half the funding is for capital expenditure and the other half for services such as advocacy, person-centred planning, supported living, and services for people moving out of long-stay hospital. The capital budget is aimed at helping people with challenging behaviour, children and young people with complex needs, and supported living for people living with older carers. Initial progress was clearly a little disappointing to SSI inspectors in 2001:

All but one council had established learning disability partnership boards. However, most had not yet registered to establish pooled funds under Health Act 1999 flexibilities. We found that partnership working offered many advantages, but that implementation needed to be closely managed, as timescales could easily slip. The rapidly changing health scene added to the need to keep a firm grip on timescales (Cope 2003 p.6).

The *Valuing People* Support Team of 11 people reports to ministers. Formed in late 2001, its aim was to achieve improvements for adults with learning disabilities, although with some perspective on services for children and young people. The Support Team's 'main role is to help Partnership Boards make the changes proposed in *Valuing People* and provide a link to what is happening at national level' (Department of Health 2003 p.9). During its first year the Team focussed on supporting Partnership Boards, encouraging the further development of person-centred planning and working with self-advocacy groups.

The Learning Disability Task Force (LDTF) started work in December 2001 with the task of monitoring the implementation of the White Paper objectives and identifying barriers to improvement. According to the 2003 annual report this new body has four tasks

It is trying to do four things for learning disability: champion change nationwide; show how people who use learning disability services are part of everything it does; check that *Valuing People* happens everywhere; report to [the government] on how things are going and what it thinks [the government] need to do' (p.10).

The most recent annual report from the Learning Disability Task Force (2004) opens with a list of 13 'good things that have happened this year', including:

- the extension of choice and control to more people with learning disabilities,
- the expansion of person-centred approaches to services,
- greater numbers of people receiving direct payments (although progress has been pretty slow and non-existent in some local authorities),

- greater participation in local, regional and national discussions and decision making,
- more accessible information on services and rights,
- more attention paid to how money is being spent on services for people with learning disabilities and their families (although it is almost impossible to find measures to show just how much is spent),
- the beginnings of attention paid to people from minority ethnic communities, although by no means enough is being done,
- financial support for advocacy groups and the new Helpline, and
- the establishment of a group involving people with learning disabilities by the National Care Standards Commission.

However, there are a number of areas where improvement is still required, and most of the report is devoted to those gaps. We shall be picking up these themes as we move through the evidence in this chapter.

The observations made by the LDTF are mirrored in other reports on progress since 2001. According to the Department of Health's 2003 annual report on learning disability services, most councils reported action to give people with learning disabilities more control over their lives, and more choice over with whom, where and how they live. They were doing less well in relation to helping carers, helping people with learning disabilities get access to health care, setting up arrangements for checking service standards in health and social care, or planning staffing needs and training requirements for the future (Department of Health 2003e).

The final summary of inspections of social care services for people with learning disabilities by the SSI, carried out in 2001 but not published until 2003, drew equally forceful conclusions about the need for improvement, although again noting that much had been achieved. It is helpful to quote the executive summary:

We identified that although good progress had been made in establishing partnership boards much still needs to be done if the objectives of Valuing People are to be met. In particular we found that:

- fragmentation of organisational responsibilities, assessment and service delivery meant that children and young people with learning disabilities were often poorly equipped to make the transition to adult services;

- without high quality person-centred planning , good information and, where necessary, the support of an advocate, opportunities for increased choice and control over their lives was empty rhetoric for many people;
- more needed to be done to win the ‘hearts and minds’ of carers if service users were to take advantage of new inclusive services. Carers often needed to see evidence that new services were in users’ best interests;
- there were significant variations in access to specialist health services within and between localities;
- the early progress under the umbrella of Supporting People in catering for the housing needs of people with mild to moderate learning disabilities needed to be extended to people from black and ethnic minority communities, there were often significant gaps where population numbers were small;
- although partnership boards were forming, the pace of progress would need to quicken if people with learning disabilities and their carers were to benefit from properly integrated planning and service delivery arrangements (Cope 2003 pp.2-3).

We shall draw on these three reports – from the LDTF, the Department of Health and the SSI – for more detail at various points in this chapter.

8.3 Needs

Prevalence

Prevalence studies built on counts of people registered or in contact with services consistently estimate that there are three or four people with severe learning disabilities per 1000 of the general population (Emerson et al 2001 pp.13-14). Higher rates have been found when entire populations have been screened. Prevalence rates for mild learning disabilities are 25-30 per 1000 general population when populations are screened, or 10 per 1000 when data are taken from people in contact with services.

There are differences in prevalence by age group. The estimates by Kavanagh and Opit (1998) summarised in table 8.1 were built up from data from the OPCS Disability Surveys of the mid 1980s and relate to severe learning disability. Prevalence rates by age band range from 6.3 per 1000 population in the 16-19 year-old group to 1.7 per 1000 population aged 0-4 years. Overall prevalence rates are estimated by Kavanagh and Opit to be 2.8 per 1000 for children (defined as ages 0-15 in this study) and 3.8 per 1000 for adults (ages 16 and over).

Prevalence is marginally higher for males, higher among younger people, higher among South Asian communities (this applies to severe learning disabilities, not mild), and higher among people who are poorer and people from adverse family backgrounds (this applies to mild learning disability, not severe). These associations with prevalence mean that there are some variations in numbers across the country. In terms of absolute numbers, according to *Valuing People*, there were about 210,000 people in England with severe learning disabilities and about 1.2 million with mild or moderate disability. The distribution of these numbers by age is given in figure 8.1.

Prevalence rates are growing and expected to grow over time because of increased life expectancy, the post-war baby boom, and higher birth rates among ethnic minority groups which experience higher prevalence rates. The 2001 White Paper gave an expectation of 1 per cent annual growth in the number of people with severe learning disabilities over the next 15 years.

Figure 8.2 shows the number of adults with learning disabilities in England receiving services, distinguishing those aged 18-64 from those aged 65 and over. There are few older people reported in these Department of Health statistics, partly because of survival rates and partly an artifice of the way that social care statistics are collected. Overall, there seems to have been a significant increase in the number of service users between 2001/02 and 2002/03.

In Figure 8.3 we summarise the numbers of people on learning disability registers in Wales by living arrangements. (The registers include people identified as having a learning disability who are currently known to their local authority for the purposes of planning or providing services.) The number of people on local authority registers for people with learning disabilities has grown by 27 per cent since 1990 to reach 12930 in 2003. Within this total, there has been growth in the numbers in private or voluntary residential homes and in community living settings, while the number of people in health service accommodation fell by 85 per cent from 1486 in 1990 to 221 in 2003. These changes reflect the policy of closure of long-stay hospital accommodation – obviously a major policy intention across the UK, as we have already seen – and the resettlement of people into the community. In 2003 77 per cent of people in community placements were living with parents or family (see figure 8.4).

The number of people with learning disability who had a contact with services in Northern Ireland for the period 1998/99 to 2002/03 can be seen from figure 8.6. After a period of stability between 1998/99 and 2000/01, there was a substantial increase in this number. Particularly noticeable is the increase in the number of children between the ages of 5 and 15 in contact with services.

Needs dimensions

There are many ways to describe the needs and circumstances of people with learning disabilities. The overarching need emphasised by the disability movement is independence, to include independent living, choice and control. These are also now key objectives of government policy. There are of course other perspectives and approaches, and some parents of people with learning disabilities might put emphasis on different objectives.

Here we follow the structure and discussion offered by Emerson et al (2001) in two chapters of their excellent introductory publication for the Foundation for People with Learning Disabilities. They first distinguish issues currently identified as important in the lives of people with learning disabilities:

- Empowerment, civil rights, normalisation and inclusion
- Making decisions
- Relationships
- Abuse

They then go on to describe what they call ‘the additional needs of people with learning disabilities’:

- Health needs
- Sensory impairment
- Physical disabilities
- Epilepsy
- Communication
- Autism spectrum disorders
- Challenging behaviour
- Mental health

- Dementia

We will discuss the meaning of each dimension, its importance, any changes in need over time and the scale of unmet need. The latter remains quite a challenge in most respects. For example, the 2001 White Paper described unmet needs in a number of dimensions, particularly in relation to health care, independent accommodation, day services (seen as insufficiently flexible or individually supportive), social inclusion and employment (with less than 10 per cent of people with learning disabilities in work across the country). In addition, the needs of people with learning disabilities from black and minority ethnic communities are 'too often overlooked' (p.20).

Empowerment, civil rights, normalisation and inclusion

As Emerson et al (2001) describe: 'Two ideological movements, normalisation and empowerment, have had a significant impact on services for people with learning disabilities over the last thirty years' (p.19). The normalisation movement is particularly associated with the work of Wolfensberger (1972), who argued that services and support arrangements should allow people with learning disabilities to lead as normal a life as possible. O'Brien (1986) distinguished 'five accomplishments' or positive life experiences:

- *community presence* in valued community settings;
- *choice* or autonomy in small everyday matters and larger life-defining issues;
- *competence* or the ability to perform functional and meaningful activities with whatever assistance is needed;
- *respect* in a network of people and valued roles in community life; and
- *community participation*, being part of a network of personal relationships with other people.

The civil rights and user empowerment movements stress the need for people with learning disabilities to be able to exercise control over their lives. This latter is therefore equivalent to a rights approach to social inclusion, whereas the normalisation arguments are perhaps more akin to a participation interpretation of social inclusion. Associated with the civil rights movement is the social model of disability, moving away from the focus on pathology and deficits towards the restrictions imposed on disabled people by the rest of society. One important set of needs, therefore, is associated with the social inclusion of people with learning disabilities, in all interpretations of the term.

As *Valuing People* made plain,

People with learning disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them. Many have few friends outside their families and those paid to care for them. Their voices are rarely heard in public. This needs to change (p.14).

We can therefore immediately see the range of dimensions over which successful policy and practice would need to be gauged, and we can also see the connections to the wider government agenda of promoting social inclusion, choice and control. The White Paper went on to emphasise the roles of a number of different ministries and agencies in achieving better lives for people with learning disabilities, including the social care, health, education, employment, housing, leisure and social security arms of central government, with the lead being taken by local authorities.

Consistent with what we were discussing in Chapter 4, there is evidence of growing acceptance in central policy discussions of a conceptualisation of need that accentuates the positives rather than focusing exclusively on the negatives, consistent with the disability movement, of course. The premise of *Valuing People*, for example, is that 'We focus throughout on what people can do, with support where necessary, rather than on what they cannot do' (p.14).

Simple but signal indications of steps to include people with learning disabilities are the Department of Health's publication of its new annual reports in this area in a far more accessible format and the co-chairing of the Learning Disability Task Force by someone with learning disabilities. More generally, the wider participation by people with learning disabilities in a range of consultative and decision making processes is an indication of progress. But these are still only small changes:

The Task Force believes that people with learning disabilities are still being excluded and discriminated against by services and society. This means that people with learning disabilities are still getting treated unfairly and missing out on the things that other people get. This is especially so for people with high support needs, and people from minority ethnic communities (Learning Disability Task Force 2004 p.13).

Making decisions

Associated with the social inclusion of people with learning disabilities must be their empowerment to take decisions concerning their own lives. This aim or need is captured, for example, in the mission statement of the National Council on Independent

Living (NCIL), an organisation that 'advances the independent living philosophy and advocates for the human rights of, and services for, people with disabilities to further their full integration and participation in society' (NCIL website August 2004).

As Emerson et al (2001 p.20) note:

Historically, people with learning disabilities have had little real power to make decisions for themselves, whether they were living in residential services or at home with parents. Instead, decisions were often made by others (i.e. professionals or parents) on their behalf. For many years this kind of control over the lives of people with learning disabilities was not questioned.

One response in recent government policy statements has been to encourage the development of recognition and mechanisms to allow greater decision making. Functional approaches to establishing capacity are favoured: 'people may have the capacity to make some decisions, but not others and that they may be competent at some points in time, but not at others' (Emerson et al 2001 p.21). A careful balance must obviously be struck between empowerment and protection.

Relationships

A third important area of need is relationships, particularly because many people with learning disabilities have very limited social networks, their only social interaction often being with other people with learning disabilities and with staff. Social isolation is often described as a classic feature of the impoverished institutional lives that many people with learning disabilities were forced to endure in specialist hospitals or large community facilities, but social isolation can also be a consequence of poorly supported lives elsewhere (Cummins and Lau 2003). For example, studies of moves from hospital to community residence have shown that people can be still quite isolated. In our evaluation of the Care in the Community demonstration projects some years ago, we found that rates of social contact, and the quality of those contacts as rated by service users, were quite poor, not just in the long-stay hospital environments from which people moved, but after one and five years of residence in community settings (Knapp et al 1992; Cambridge et al 1994; and see section 8.7 below). There was evidence of more control over and choice in relation to social networks in the community, but overall levels remained poor. As Emerson and Hatton (1994) point out in their review of a range of studies, observed increases in social contact rates when people move from hospital to community residence are often simply because of more frequent visits from relatives and incidental interactions with shopkeepers, and not from any increase in meaningful friendships with neighbours or other non-disabled people.

A related need is for intimate relationships, so often seen as taboo in the past (Heyman and Huckle 1995). Support for people with learning disabilities in this area is described by Emerson et al (2001) as 'very patchy'. Carnaby and Cambridge (2002) discuss the neglect of the management of intimate and personal care for people with learning disability, particularly those with profound and multiple disability.

One of the objectives set out in the 2001 White Paper is 'to enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships' (p.76).

Abuse

Emerson et al (2001) describe a number of types of abuse to which people with learning disabilities may find themselves subjected: physical, sexual, psychological/emotional, financial, discriminatory and neglect. Studies have found high prevalence rates for sexual, physical and psychological abuse (see Emerson et al 2001 for some relevant references). There have been moves to afford people with learning disabilities greater protection, and the greater awareness of these abusive practices is beginning to lead to the introduction of clearer policies and procedures to prevent abuse happening, and to support people who have been abused. Balogh et al (2001) studied the occurrence of victimisation and the perpetration of sexual abuse in young inpatients with learning disabilities. Victimisation was more frequent than perpetration. A recent review by White et al (2003) notes that it is too simplistic to attribute abuse to 'individual deviancy and culpability', and a broader view is needed if preventive strategies are to be developed. It may also be necessary to redefine the nature of the problem. The Learning Disability Task Force (2004 p.54) report expressed concern that words such as 'bullying' and 'abuse' distract attention from what is really happening. The report argues that we should be using the terms that are more widely employed, such as 'harassment, hate crimes, assault and rape', and in this way encourage agencies to take these crimes more seriously.

Health needs

Many of the health needs of people with learning disabilities go unrecognised, partly because of communication difficulties, while others go untreated because of poor responses to needs by health care professionals and services. Some of the health problems faced by people with learning disabilities are iatrogenic, including the side effects from the treatment of challenging behaviour with antipsychotic medications and

the lifestyle consequences of some service models: linked to poor diet, obesity and physical inactivity (Robertson et al 2000, 2000a).

The 2001 White Paper devoted some attention to the unmet health needs of people with learning disabilities. The problem is that access has been haphazard, and generally very poor. Health screening services are rarely used (see, for instance, the evidence in Wilson and Haire 1990), diagnosis and treatment of some specific medical conditions (including heart disease, hypothyroidism and osteoporosis) are poorly accessed, there is an over-dependence on psychotropic drugs to manage challenging behaviour despite the absence of evidence that they are effective (Brylewski and Duggan 1999), and potential health complications arising specifically because of learning disability are often overlooked. A number of action plans are set out in the White Paper to reduce health inequalities, particularly for people from minority ethnic communities. The objective set by the government was:

to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary (p.59).

Numerous studies have documented the unmet health needs of people with learning disabilities. We mention just a few. Barr et al (1999) pointed to the 'major gaps...in the ability of current primary health services to respond to the needs of people with learning disabilities' in Northern Ireland. Particular areas of 'neglect' related to cardiovascular status, sensory deficits, mobility and aspects of sexual health. Powrie (2003) carried out a pilot study in Scotland with primary care practice nurses. These respondents described a number of communication barriers that prevented access to health screening and treatment. Cumella et al (2000) report the considerable unmet oral health needs of people with learning disabilities. Morgan et al (2000) describe health care use patterns for people with learning disabilities in South Glamorgan, noting the continued influence of the local learning disability hospital.

As life expectancy for people with learning disability continues to improve, it becomes increasingly important to identify and respond to age-related needs (Holland 2000). A longer life span creates opportunities but also carries resource implications for service provision, especially if one considers that family (particularly parent) carers are themselves ageing. ('Many people with learning disabilities now in their 50s and 60s were not expected to outlive their parents', Secretary of State for Health 2001 p.103.) Until recently there was little research on how best to support people in the community in later life, what their needs and preferences are or would be, or how to meet them (Fitzgerald 1998), although an issue of the *Journal of Applied Research in Intellectual Disabilities* in 1997 and another in 2001 were focused on health and ageing. A summative report from the WHO drew the papers together (WHO 2001a; Janicki 2001).

Cooper (1997) describes how people with learning disabilities aged 65 years and over compared unfavourably with adults with learning disabilities aged 20-64 in terms of use of services.

Elderly people received less day care, less respite care, and were less likely to have a social worker and receive input from most health services than the younger group. Chiropody was an exception. Those receiving psychiatric services did so through the learning disabilities specialist services only. Those with an additional psychiatric disorder were more likely to receive services, but results still favoured the younger group. Services were better accessed by those living in residential care (Cooper 1997 p.331).

However, the SSI summary report argued that people living in ordinary (supported) housing were more likely to use mainstream health services (Cope 2003).

Walker et al (1996) similarly point to age discrimination for older people with learning difficulties leaving institutional care. They tended to live in small group homes, as resource constraints did not allow use of individual housing units even where this may be more appropriate. Individuals were unlikely to have access to learning disability community services such as day centres, domiciliary services or respite care which could improve their quality of life, and there was very little contact with 'mainstream' older people's services. Many did not have relevant assessments of their (usually limited) care packages, and rarely was there any planning for the future. They were socially isolated, even when living with their families. Family carers were often powerless to improve participation in activities by their learning disabled relatives or themselves. Few had advocates. In general, need was narrowly constructed in policy and practice contexts (Walker and Walker 1998).

Holland (2000) describes 'some key biological, psychological and social issues relevant to how ageing might particularly effect people with learning disabilities' (p.26). Uncoordinated approaches from health and social services to address the needs of this group appears to be hampering the delivery of better services:

Learning disability services remain unprepared for the changing needs of older people with learning disability and ... generic services for the elderly are not readily accessible' (p.29; and see Fitzgerald 1998).

The 2003 annual report from the Department of Health (2003e) gave great emphasis to meeting the health needs of people with learning disabilities. A number of initiatives are described, relating to Health Action Plans, finding health facilitators, ending discrimination against people from BME communities, getting people with learning disabilities registered with GPs and a variety of initiatives regarding specialist services (see chapter 7 of that report for details). The report also announced that research would

look at how people with learning disabilities use health services. Despite these plans, the following year's report from the Learning Disability Task Force remained critical:

The Task Force wants specialist learning disability health services to change the way they work so that they really help adults and children with learning disabilities to benefit from the same services that other people use. In some places this is starting to happen. But there are still too many stories of people not being supported properly, people being excluded from health care or being offered a special service that is just for people with learning disabilities (Learning Disability Task Force 2004 pp.43-44).

The Task Force also advocated better health care for family carers, training for staff working in health services so they better appreciate the health needs of people with learning disabilities. One of the concerns expressed in the report is the continuing confusion of mental health with learning disability. In its response (in its own 2004 report) the Department noted that it had issued a report, *Building on the Best: Choice Responsiveness and Equity*, concerning access to health services. It was hoped that the new GP contract would ease access for people with learning disabilities, and public health initiatives should also contribute (Department of Health 2004b).

Sensory impairment

People with learning disabilities have a higher prevalence of sensory impairments than is found in the general population, as shown in various national disability surveys. Emerson et al (2001) suggest that the prevalence may be as high as one in three, although epidemiological studies offer quite a wide range of estimates. People with learning disabilities therefore have needs related to quite high rates of hearing loss and visual impairment. Hatton et al (1996) found that people with sensory impairment with the greatest skills perversely received more staff support than those with fewer skills.

Physical disabilities

From the Leicester Learning Disabilities Register, McGrowther et al (2002) reported that 40 per cent of South Asian adults and 43 per cent of white adults had a physical disability. Their finding is consistent with other evidence. As Emerson et al (2001 p.29) note:

Many people with learning disabilities also have physical disabilities. Many who have severe learning disabilities have an associated disorder affecting movement. Cerebral palsy and other motor impairments ... adversely affect speech, mobility and length of life.

Consequently, a wide range of support and treatment services will be needed by a number of people, with those services most likely needing to come from a range of agencies.

Epilepsy

The prevalence of epilepsy among the learning disabled population is much higher than in the general population: *Valuing People* suggested that 'the rate of "active" epilepsy for people with mild or moderate training disabilities is 5 per cent compared to a normal rate of 0.5 per cent in the general population' (p.101). The rate could be 50 per cent for people with profound learning disabilities. Kerr et al (2003) suggested as many as a third of long-stay residents in a Glasgow hospital with epilepsy. Prevalence also increases with the severity of disability (Bowley and Kerr 2000). The consequences of epilepsy can clearly be very distressing for people with this condition, and also stressful for their carers.

Communication

Many people with learning disabilities have communication difficulties because of their own problems with speech, hearing or the behavioural aspects of language (as with some people with autism). But communication can also be problematic because of the unimaginative or unhelpful approaches of services. Emerson et al (2001) suggest that between 50 per cent and 90 per cent of people with learning disabilities have communication difficulties. The summary of social care inspections by the SSI noted that 'Service users with more complex needs had a harder time of things, as their extra communication needs made it more difficult to participate meaningfully in assessments, reviews and planning meetings' (Cope 2003 p.4). The LDTF (2004) report includes a chapter on communication, and what needs to be done to improve abilities in this area. This is clearly fundamental to the extension of choice and control, for example.

Autistic spectrum disorders

One particular learning disability is autism, although the condition often goes unrecognised among people with severe and profound learning disabilities. Levels of ability vary markedly across the spectrum. People with autism have impaired social relationships, which generate a range of needs. 'Throughout their lives the majority of people with autistic spectrum disorders require educational, social, psychological and therapeutic interventions' (Secretary of State for Health 2001 p.102). Whether their

needs are met or unmet, they can generate very high costs, as we describe later (Jarbrink and Knapp 2001). Communication difficulties and repetitive activities and interests generate further difficulties, and there is a higher risk of self-injurious behaviour than in the general population of people with learning disabilities (Collacoatt et al 1998). There are long waiting times for early diagnosis of autistic spectrum disorders (Secretary of State for Health 2001).

Challenging behaviour

One of the most frequently discussed characteristics in the learning disability field is challenging behaviour, although it is displayed by only 5 per cent to 15 per cent of people with learning disabilities. However, the focus on challenging behaviour may be disproportionate: Reiss (1988) estimated that for every person with learning disabilities in the USA 'who needed treatment for a severe behaviour disorder, there were 10 who needed training in social skills, and two who needed treatment for depression' (Parmenter 2004 p.26).

People with challenging behaviour:

show behaviours which present a significant challenge for those caring for them, ... such as aggression, destructive behaviours, self-injury and a range of other behaviours which either place the health or safety of the person or those around them in jeopardy or are likely to lead to the persons' exclusion from community settings (Emerson et al 2001 p.36; and see references there to primary research).

Challenging behaviours may develop because of specific syndromes, because of 'functional and adaptive responses to challenging situations', or linked to psychiatric disorders. Behavioural and pharmacological approaches have been taken to treat some forms of challenging behaviour. But

... people with learning disabilities in the UK who show challenging behaviour are much more likely to receive antipsychotic medication than positive behavioural support' (Emerson et al 2001 p.37).

Robertson et al (2000a) offer some recent evidence on rates of antipsychotic use from across a range of different care settings. A worry is that there is little evidence that the widely used antipsychotic medications are effective (Brylewski and Duggan 1999; Secretary of State for Health 2001 p.103). An HTA-funded trial (NACHBID) is currently underway (coordinated by Peter Tyrer at Imperial College London) in this area.

More generally, 'the provision of effective support for people with challenging behaviour has been one of the most significant issues facing community services for some years' (Joyce et al 2001 p.130). As we discussed in section 8.2, the report of the project group chaired by Jim Mansell focussed attention on these issues and drew up recommendations that have been influential over the past decade (Department of Health 1993). The study by Joyce et al (2001) in three London boroughs found that 20 per cent of people with challenging behaviour were in out-of-borough placements. The study also found that 24 per cent had some form of placement breakdown, 24 per cent had come to the attention of the police, and 30 per cent had been excluded from day care.

Halstead (2002) carried out a 'mini review' in the field of forensic intellectual disability looking at individual characteristics, needs, social exclusion, quality of life, autonomy, disability, ethics, management of behaviour, participation in the criminal justice system and a range of professional issues (service design, staff attitudes and attributions, multidisciplinary and multi-agency working, staff burnout, therapeutic interventions, training). The overwhelming impression gained from the review was of the large gaps in the evidence base, particularly in relation to levels of acceptable risk and to professional development and practice.

Mental health

People with learning disabilities have a higher risk of mental health problems than the general population (Deb et al 2001), but have fewer 'protective factors' such as social support. Prevalence rates as high as 40 per cent have been suggested. Emerson et al (2001) point to the difficulties of assessing mental health needs, and therefore in establishing prevalence rates, partly because of difficulties in distinguishing some psychiatric needs from challenging behaviour (and see Mason and Scior 2004; and Dossetor and Nicol 1990). Another reason for under-recognition would be the communication limitations of some people. Standard diagnostic criteria may also not be appropriate. As we will note later there is little systematic evidence on the effectiveness or cost-effectiveness of mental health treatments for people with learning disabilities.

Drawing their sample from the Leicester Learning Disabilities Register, McGrowther et al (2002) collected information for over 2500 South Asian and white adults. Despite few differences in needs, only 62 per cent of the South Asian group used psychiatric services compared to 77 per cent of whites. In an Oxford region study, McCarthy and Boyd (2002) looked at specialist health service use during their adolescence and early adulthood (mean age 27 years; range 22-35) by 80 people who as children were included in an earlier study because they had learning disabilities and mental health problems (Gath and Gumley 1986). In childhood, 95 per cent lived with their parents, and at follow up 73 per cent remained there, with 21 per cent in staffed group homes.

Every sample member had contact with primary care services during adolescence, and three-quarters had yearly or more frequent thereafter. Only 16 people (one fifth of the sample) had contact with a learning disability psychiatrist during adolescence (with 10 reporting regular contact); nine with a clinical psychologist; four with an educational psychologist and 14 with a community nurse. Only one third of those with either a behaviour or psychiatric disorder were in contact with mental health professionals, and they were *not* higher users of other health or social care services.

Generally, it has been argued that there is under-funding and poor provision of mental health services for people with learning disabilities (Royal College of Psychiatrists 2003, Bouras and Holt 2004). For a similar conclusion but from a different perspective see Mind's information fact sheet *Mental Health Problems and Learning Disabilities* (available from the Mind website).

Dementia

With the increasing longevity of people with learning disabilities, health problems associated with ageing also become more prevalent, as we have already noted. Dementia is one of those growing needs, and some people with learning disabilities (such as those with Down's Syndrome) have a higher risk of developing Alzheimer's disease than the general population. Many people would develop these health problems in mid adulthood.

McCarthy and Mullan (1996) review the evidence on older people with a learning disability. Almost all of the evidence they cover pre-dates the 1990 reforms in the UK, and much of the evidence anyway comes from outside the UK. The paper offers a helpful description of the circumstances, needs and service arrangements for what is described as 'an increasing population who will have high health and social care needs' (p.497). Cooper (1997) looks at the prevalence of psychiatric disorder for people on the Leicestershire Learning Disabilities Register.

Stalker et al (1999) found that most members of their sample of 20 people with learning disabilities and dementia were able to express clear preferences but many had few opportunities to participate in decisions about their lives. Few, for example, could choose 'where they lived, what they did during the day or who supported them'. See also the recent Scottish study by Wilkinson et al (2004).

8.4 Funding and expenditure

Trends

According to *Valuing People*, expenditure on health and social care services for adults with learning disabilities in England in 1999/2000 exceeded £3 billion, of which £1.4 billion was on health care. In the same year, health and social care expenditure in Wales was £193 million, with a much smaller proportion (about 29 per cent) by the health service (Cabinet Statement from Minister for Health and Social Services, 1 November 2001). Apparently Wales has a proportionately higher level of expenditure than England or Scotland.

It is interesting to compare the figure for England in the 2001 White Paper with a more recent and with an earlier estimate. The more recent figure, for 2002/03, would be approximately £3.75 billion. (These are our calculations from figures kindly provided by Alistair Brechin of the DH. They assume that NHS expenditure in 2002/03 was the same as in 2001/02, i.e. £1.5 billion.)

The earlier estimate comes from Smith et al (1995) and relates to 1986: £1.43 billion at 1986 prices. These are comprehensive figures that cover not only NHS and local authority expenditure but also expenditure by the DSS. The last of these included not just income support payments for residents in care homes but a wide range of benefits paid to people living in other settings. Smith et al also calculated the non-reimbursed costs falling to voluntary and private sector providers, amounting to £45 million and £39 million, respectively. If we exclude these for the moment (leaving £1.35 billion expenditure by the public sector) we can make a direct comparison with the estimated figure for 2002/03, because the latter will have included payments formerly routed via the DSS. Adjusting to 2002/03 prices by applying the HCHS inflator to NHS expenditure, and the PSS inflator to social services and DSS expenditure, the 1986 figure is equivalent to £2.94 billion. One problem with this comparison is that people with learning disabilities living in ordinary or supported housing will be in receipt of social security payments that are not included in the 2002/03 figure of £3.75 billion, whereas they were included in Smith's estimates for 1986. In other words, even though we have not been able to include these social security expenditure elements, there has clearly been a substantial increase in (inflation-adjusted) spending on people with learning disabilities. (To make more detailed or precise calculations would take much more time than we have available.) However, it has been suggested that 'the commitment of the governments of industrialised countries to neoliberal economic policies that were in the ascendancy throughout the 1980s and beyond' (Parmenter 2004, and see Parmenter 1999) lessened the social and political commitment to the field and 'a more parsimonious financial commitment to the needs of people with disabilities in general'.

Looking over a slightly longer period, Evandrou and Falkingham (1995) report how the balance between HCHS and social care expenditure changed between 1977 and 1994. In the earlier year, health spending accounted for 73.8 per cent of the total, compared to 61.2 per cent by 1994. Over the same period the proportion of the total spent on residential care and inpatient services fell from 82.3 per cent to 67.9 per cent.

Figures calculated by Jones and Wright (1996) from data provided by a small but representative sample of local and district health authorities indicate that the health spending proportion was 55.1 per cent in 1993, somewhat lower than the figure offered by Evandrou and Falkingham (1995) which they took from Department of Health reports.

By 2001/02, if we draw together data from various sources, our own rough calculation would be that 46 per cent of total HCHS and social care spending on people with learning disabilities was by the NHS, indicating a further fall, although there is a complication in that funding not included in the Evandrou calculation or the Jones sample-based calculation (social security expenditure on people in care homes) was gradually being replaced by local government PSS expenditure over the course of the 1990s. Social care expenditure appears to have overtaken NHS expenditure in 1996/97 (see the figures on p.18 of the White Paper; Secretary of State for Health 2001), and the two will have moved farther apart in 2002/03 with the transfer of preserved rights funding to local authorities.

These trends clearly reflect two important, long-term, linked policy intentions: to move care out of long-stay hospital settings, and to shift the balance of responsibility away from the health service and towards local authorities. It is not clear, however, whether or to what extent funding from outside the health and social care sectors – such as Supporting People funding for housing or education department funding for further education classes – is substituting for, or adding to expenditure by social services departments or the NHS. Jones and Wright (1996) found no such evidence ten years ago, but times have changed.

Our commentary in this section is hampered a little by the limited data available on learning disability expenditure, something that the Learning Disability Task Force is currently endeavouring to address. It has set up a sub-group to 'find out how much is being spent on adults with a learning disability. This will include spending in health services, care services, housing services and adult education. They will also look at the ways money is being spent' (LDTF 2004 p.35). The group will also try to estimate the cost of meeting all of the *Valuing People* objectives over the next five years. There is also an intention to project service costs over longer periods, perhaps for up to 10 years. Currently, there are no results from these activities.

One related concern expressed by the Task Force was that not all of the £20 million capital budget allocated by the Learning Disability Development Fund had actually been spent on learning disability services: seven strategic health authorities had failed to spend the money as intended. Overall, the amount of money spent through the Development Fund is less than planned (Department of Health 2003e p.81).

NHS expenditure trends

Hospital and community health services identified as being provided for people with learning disabilities accounted for 5 per cent of total NHS HCHS expenditure in England in 2001/02 (House of Commons Select Committee on Health Memorandum 5 January 2004). Total NHS expenditure on hospital services was £22.6 billion in 2001/02, 2.5 per cent of which was identified as being spent on people with learning disabilities, while the proportion was much higher (18.9 per cent) for the total community health expenditure of £5.5 billion. When the distribution of this expenditure is examined across the lifespan (as reported in the same memorandum) we see that the learning disability proportion of overall national HCHS spending was as high as 22.2 per cent for the 5-15 age group and 9.9 per cent for the 16-44 age group, but as low as 0.5 per cent for the population aged 65-74 and 0.1 per cent for the population aged 75-84.

The same Select Committee Memorandum gave details of NHS expenditure on various community care services over a five-year period, one detail of which is relevant to this discussion. At 2001/02 prices, expenditure on community learning disability nursing grew from £330 million in 1997/98 to £411 million in 2000/01 but apparently fell back to £387 million in 2001/02.

Figures on the DHSSPS website in Northern Ireland compare activity rates, expenditure and unit costs for supporting people with learning disabilities in the four home countries. The average costs are summarised in table 8.2 below. They provide evidence of differences between countries in terms of both levels and costs of activity, although some of the differences arise because of the ways that the data are collected and reported. It is therefore difficult to know how much can be learnt from these cost comparisons without a more intensive scrutiny of the statistics and of course the data collection procedures in the local systems of care.

Forsyth and Winterbottom (2002) compared expenditure on learning disabilities by health authorities across England in 1998/99 in relation to the estimated numbers of people with learning disabilities (by summing DH data on the numbers of people in registered homes and supported at home). Service expenditure per person with learning disability ranged from £4230 to £27990, around a median of £10260 (the mean is not

reported). Notwithstanding a number of limitations (inevitable in this kind of calculation because of the nature of the data available), the paper therefore reports wide variations in NHS expenditure per person. Forsyth and Winterbottom found a significant positive correlation between mean NHS expenditure per person and the proportion of placements funded by the local authority, implying that lower ratio health authorities have more 'imported' placements from other regions. The converse is also true: higher ratio authorities are 'significantly likely to be net exporters; these are smaller, urban regions' (p.204). Currently 'receiver' areas fund health care for these placements from other authorities and service level agreements (arranging for transfer of funds to cover these costs) were not in place.

Local authority expenditure trends

Figure 8.6 shows that, in England, there were increases in the level of expenditure on social services for adults with learning disabilities aged under 65 well above the rate of inflation for the period 1994/95 to 2002/03. In absolute terms, the level of expenditure in 2002/03 was over 2.3 times that in 1994/95. Part of the increase would have been due to the phasing out of preserved rights funding from the social security budget and the transfer to local government of responsibility for funding new placements. The 30,000 or so younger disabled people still with preserved rights at the time of the 2001 White Paper were to have their funding transferred to local authorities forthwith (to take effect from April 2002), along with responsibility for assessment and care management. It was argued by the Department of Health that this would give them greater choice about where they live. This explains the jump in local authority expenditure on residential care between the final two columns of figure 8.6 (for 2002/03).

Over the same period since full implementation of the 1990 Act there were other changes in proportional expenditure by local authorities. There was, for example, a noticeable reduction in the proportion of total social services expenditure on day care, and significant increases in the proportions spent on home care and supported and other accommodation services (compare figures 8.7 and 8.8). Overall, residential care home placements continue to consume the largest proportion of resources, with around 52 per cent of expenditure in 2002/03. A Memorandum from the House of Commons Select Committee on Health (5 January 2004) details local authority expenditure on residential care for adults aged under 65 with learning disabilities. At 2001/02 prices, expenditure grew from £631 million in 1997/98 to £828 million in 2001/02.

The proportion of total (net) expenditure on personal social services in England accounted for by adults aged under 65 with learning disabilities remained almost exactly constant at 14.3 per cent between 1997/98 and 2001/02 (Hansard 1 September 2003, column 938W). Over the longer period, according to the Department of Health (2003e), the proportion of local social services expenditure allocated to learning disability

services has grown from 7 per cent in 1983 to 10 per cent in 1993 and 14 per cent in 2002. The Department notes that it is up to local Partnership Boards to identify what is needed to meet the needs of people with learning disabilities, and to allocate resources from local authorities, primary care trusts and other NHS bodies. The Learning Disability Task Force has commented on the difficulty of getting clear information about how much is spent in each locality on learning disability services.

Figure 8.9 shows the changing pattern of expenditure in Wales, although in less detail. These figures relate to total identified social services on people with learning disabilities over the period 1997/98 to 2002/03. They suggest significant increases in the levels of expenditure, above inflation rates. Particularly noticeable is the increase in expenditure residential care services between 2001/02 and 2002/03, again as a result of the final transfer of preserved rights funding. Between 1997/98 and 2002/03, the proportion of total expenditure going to residential care services increased from 49 per cent to 55 per cent (compare figures 8.10 and 8.11).

Although not illustrated here, there is plenty of evidence of wide variations in expenditure on learning disability services across the country. According to the 2001 White Paper:

We know that expenditure on and costs of services for people with learning disabilities vary significantly from one authority to another. The scale of these variations is difficult to justify, and we believe that there is scope for the money currently devoted to learning disability services to be used more effectively. The application of Best Value principles will achieve better value for money (Secretary of State for Health 2001 p.95)

Broad cost impacts and variations

As we have pointed out in other chapters, the needs of many people who are social care service users extend beyond the social care field, and we have just seen the importance of health care service use. Moreover, in section 8.3 we discussed needs under a number of heads suggested by Emerson et al (2001), the meeting of each of which could lead to expenditure across a number of social care and non-social care budgets. Different service arrangements will generate different patterns of expenditure and potentially different combinations of incentives to coordinate action, pool resources, pursue overall efficiency and tackle inequity.

We can illustrate the main patterns of cost with results from five studies. The first is a detailed national costing of services supporting people with learning disabilities based

on OPCS Disability Survey data of the mid/late 1980s and price levels for 1994/95 (Kavanagh and Opit 1998). The second is a major cross-sectional study of a range of accommodation settings, including village communities and supported housing (Hallam et al 2002). We then describe a national cost-of-illness study for autism. The fourth piece of work was concerned with people who left long-stay hospital residence, following them over a twelve-year period (Hallam et al 2004). Finally, we offer evidence on the extent of cost variation within a sample of service users and some explanation of the sources of variation. We should note that, although all five studies were carried out (partly or wholly) at the PSSRU, this does not really constitute a selection bias. As far as we can tell, the majority of studies of economic aspects of learning disability services in England have actually been conducted in PSSRU (almost always in collaboration with specialist learning disability research teams elsewhere).

National cost components

Kavanagh and Opit (1998) carefully analysed data collected in the Disability Surveys of the mid 1980s to estimate the numbers of people with learning disability by degree of severity, and to describe patterns of service use and the associated costs. They updated those costs to 1994 price levels, and also made adjustments to the costs so that they reflected service provision patterns that year. They undertook this exercise separately for children and adults. The numbers of people by care setting summarised in table 8.3 are Kavanagh and Opit's estimates of numbers in 1994, rather than direct observation. Their cost calculations show that total costs for adults were approximately £3.1 billion at 1994/95 prices, of which almost exactly £2 billion was expenditure by the NHS and local authority social services departments. In fact, at the time, there was almost an equal three-way split between NHS funding (31.4 per cent of the total; most of it by health authorities, where hospital provision continued to be the major cost element, but a small proportion by primary care services), local authority social services funding (32.8 per cent) and funding primarily associated with people living with their families or in other private household settings and incurred by people with learning disabilities themselves, their families or supported from social security benefits of various kinds (35.8 per cent).

Cost differences between accommodation settings

A major study was commissioned by the Department of Health to address questions about the relative merits of village communities (favoured by organisations such as Rescare – with particular support from families of people with learning disabilities), NHS residential campuses (often developed on the sites of, sometimes in some of the same buildings as, long-stay hospitals) and dispersed housing. We will draw a number of results from this study in this chapter (for the core findings see section 8.7). The settings

and residents were drawn from across the UK and Ireland. The economic evaluation included a careful costing of each accommodation setting and the comprehensive measurement of all services used by three large samples of people. The costs are summarised in table 8.4 (full details in Hallam et al 2002).

Accommodation and day activities together made up most (almost 100 per cent) of the total cost of support, the remainder being hospital services and community-based professionals. The cost of hospital and community services was significantly higher for people in dispersed housing than for those in residential campuses, where support from health care professionals was more likely to be included in accommodation arrangements. Overall, the total cost of support was significantly lower for village communities than for residential campuses or dispersed housing. The study went on to examine the sources of cost variation between individuals (which we do not detail here). Comparison of village communities and dispersed housing schemes found that both accommodation settings were associated with particular benefits, with different settings appropriate for people with different needs and preferences. The study supported the development of a range of models, as acknowledged in the 2001 White Paper, provided that residents were given genuine and informed choices about their accommodation.

Autism: national cost estimates

Although not providing evaluative evidence, cost-of-illness calculations (as they tend to be called in the health economics literature) give an overall indication of the economic consequences of an illness, disorder, condition or disability. As well as the limitation of not providing evaluative evidence, there are sometimes complications around the methods of calculation, the difficulties in dealing with comorbid conditions, and of course the absence of evidence on quality of life and outcomes. Notwithstanding those limitations, it can be useful to highlight the direct and indirect cost implications of the total prevalence of a health problem or disability. One such study looked at the total economic impact of autism in Britain (Järbrink and Knapp 2001). The lifetime costs for someone with autism and additional learning disability are given in table 8.5. The table also gives the costs for somebody with high-functioning autism (Asperger's syndrome), technically not a learning disability. The former cost, for somebody with autism and learning disability, suggests – very conservatively – a lifetime cost in excess of £2.4 million. Those costs are spread across a range of sectors (public, voluntary, family) and agencies.

Costs comparisons over time

The needs of service users are very likely to change over time, if only as a result of age-related health deterioration, and the services provided may therefore also change both

to meet changing individual preferences and needs and in accordance with developments in service philosophy. Evidence was gathered on service use and costs twelve years after a group of service users left long-stay hospitals for community living arrangements under the Care in the Community demonstration programme (Renshaw et al 1988). Comparisons could be made between the circumstances and lives of people in the study as they were in hospital, one and five years after leaving (the full results for which were reported by Knapp et al 1992 and Cambridge et al 1994, respectively) and twelve years after leaving (detailed in Hallam et al 2004).

Community care at the twelve-year follow-up remained more expensive than hospital-based support, although the average cost was lower than after one or five years in the community. Service users were living in a wide variety of accommodation settings, with day-to-day management responsibility for facilities falling to NHS trusts, local authorities, voluntary agencies, private organisations or (in a small number of cases) services users themselves. After standardising for users' skills, abilities and behaviour levels, costs in minimum support accommodation were significantly lower than in residential and nursing homes, costs in staffed group homes significantly higher, and costs in hostels slightly lower. The study also reported quality of life improvements for this cohort of people, suggesting long-term quality of life improvements can be achieved at a cost little different in the long-run from that for hospital care.

Cost variations

Valuing People noted that 'expenditure on and costs of services for people with intellectual disabilities vary significantly' (Secretary of State for Health 2001 paragraph 8.18). Few studies have accounted satisfactorily for such variation, although the most consistent finding is that higher costs are related to higher levels of need. The final study summarised in this section examined cost variations. Data were collected in 1996 as part of a study designed to develop 'resource groups' and 'benefit groups' for people with learning disabilities (see below). Information was obtained on some of the characteristics of over 2000 adults with learning disabilities living in residential accommodation supported by eleven NHS Trusts, four voluntary providers (including housing associations) and three large and several small private providers spread across England. Service use and costs data were gathered for a sub-sample of about 900 people (full details in Knapp et al 2004).

There were marked total cost differences across the sample, ranging from £220 for one person's weekly care to as much as £1570 for another person (1996/97 prices). Multiple regression analyses could statistically explain one third of the observed cost variation, indicating that the services used by individuals are responding in part to the individual

characteristics and features of the care settings measured in this study. Nevertheless, two-thirds of the observed cost variation cannot be explained (statistically) by the cross-sectional analysis.

Costs were found to be higher for people with more severe learning disability and displaying greater levels of challenging behaviour. The cost links are non-linear and interdependent: at low levels of learning disability there is a simple positive linear relationship between costs and behaviours; at higher levels of disability (where there were in fact relatively few sample members) there is a slight curvilinear cost-behaviour relationship, although costs are still generally higher for people with more challenging behaviour problems. The impact of learning disability on cost is mediated through both the sector of accommodation (there being a lower gradient relationship in the NHS sector than in the private/voluntary sectors) and through the size of accommodation setting (the impact of learning disability on cost being slightly less in larger facilities). These significant associations suggest that larger facilities – and these two features are correlated – have greater potential to spread the responsibility for supporting challenging behaviours and learning disability, respectively, across the staff complement.

The study also found direct cost-raising effects for sector and size of facility, in addition to those linked to degree of learning disability. Generally, NHS facilities were more expensive than private/voluntary facilities, other things being equal. However, as just noted, the cost difference between the sectors was not straightforward, but linked to facility size and resident learning disability characteristics, and we should therefore be cautious about drawing conclusions concerning inter-sectoral differences from a sample that draws data from a relatively small number of independent sector providers.

The scale of facility, in this case measured by the number of residents in the home during the year, exerted an influence on cost, with an interesting difference between the sectors. NHS facilities clearly enjoyed economies of scale, with cost being just under £2 lower per resident week for each additional resident in the facility. In part this is because of the inclusion in the NHS sample of some people living in quite large hospital facilities. On the other hand, the voluntary/private facilities appeared to be facing diseconomies of scale, with each additional resident in the home generating an additional cost of £2.48 per resident week across *all* residents.

Interpreting this cost evidence

What do these five illustrative studies tell us? First, the costs of supporting people with learning disabilities range quite widely, because of the variety of health, social care, housing and other services required to meet the needs of individuals. We have already

noted that many needs go unmet, and a more comprehensive system of support would broaden the cost impact.

Second, there are quite marked differences between accommodation settings, both in the total cost and in the component elements. The current policy emphasis on offering more people with learning disabilities the opportunity to live in supported or ordinary housing clearly has funding implications that will need to be thought through.

Third, the costs of supporting people do not stand still. As an individual's needs change, so should the service responses to those needs, and so usually will the costs also change. The 12-year follow-up study has found that needs associated with ageing do not necessarily push up costs greatly. Indeed, quality of life improvements for former long-stay hospital residents were achieved without costs exceeding those previously incurred in the hospital setting. With the increasing longevity of people with learning disabilities (see above) this becomes very relevant.

Fourth, there are also marked variations of costs within the cross-section particularly associated with the severity of learning disability and the presence and severity of challenging behaviour. Whilst there is a tendency for people with greater needs (defined in various ways) to have higher costs - which suggests some success in targeting - much of the inter-individual variation in cost cannot easily be explained by observed or measured characteristics, perhaps supporting the previously described evidence on unmet needs.

Finally, these and other studies have generally found that higher costs are associated with better outcomes (measured as improvements in the well-being and quality of life of service users and their carers). But the association is far from straightforward. Simply allocating more money to a service or system will not guarantee outcome gains.

Direct payments

As we have noted in other chapters, the take up of direct payments has been slower than the government and many other people had hoped. The 2001 White Paper was just one of a number of official documents offering encouragement in this respect. Direct payments would enable people with learning disabilities to take control of their own commissioning of (many) services. The Department of Health (2003e) reported that 736 people with learning disabilities were getting direct payments by September 2002, a doubling of the number in one year but still a very small total. There were still authorities where there was no one with a learning disability in receipt of direct payments. According to the summary of SSI inspections in 2001:

The use of direct payment schemes, where service users and families are given the option to purchase some or all of their own care, was in infancy. In only one council was there a reasonably high take-up of this option by people with learning disabilities (Cope 2003 p.3).

The government soon announced the establishment of a Development Fund to promote wider use of direct payments, allocating £9 million over a three-year period from April 2003. One particular concern was the small number of people with learning disabilities. One of the hurdles to be overcome was the establishment of bank accounts, and the Department of Health's 2004 learning disability annual report describes the government's initiatives in helping people in this respect (Department of Health 2004b). Person-centred planning and better advocacy would also provide support for people contemplating and taking up direct payments.

Three reports in the 1990s by Values into Action (Collins et al 1997, Ryan 1999, Holman and Bewley 1999) set out the potential of direct payments, the barriers to be overcome, and action that would help to expand the take-up rate. Recently, Williams et al (2003) found that parents can be strong advocates for independence for their disabled child and for direct payments, but nevertheless reluctant to encourage the use of direct payments when they had insufficient information about such schemes and what they offered. As they note, direct payments can radically alter 'the power balance between persons with intellectual disabilities, their parents and their staff ... but it is still important to have a good, independent direct payments support scheme to enable the person with intellectual disabilities to be in control' (p.219).

Resource and benefit groups

The formalisation of decision-making about service delivery and funding in health and social care in the UK has taken a particular direction since implementation of the 1990 National Health Service and Community Care Act. Purchasing and provision have been separated and commissioning of services has become a key activity. The main players in the 'quasi-markets' that now structure care systems are looking for approaches, frameworks or tools to aid their decision-making. Although decisions based on the individual service user's needs and preferences are central to community-based care systems, it is also important to seek approaches which, when applied in the aggregate, can simplify the otherwise complex tasks of matching resources to needs and keeping within available budgets.

One approach that has been examined in a number of health care systems, starting in the US, has been to develop diagnostic related groups (DRGs). In the NHS the DRG approach was initially explored in the Health Care Framework, which classified patients' needs using health benefit groups and classifies interventions using healthcare

resource groups (NHS Information Authority 1999). The recent introduction of 'payment by results' is the result.

- *Health care resource groups* (HRGs) are sets of activities (procedures or interventions) that are clinically similar and consume similar amounts of resources.
- *Health benefit groups* (HBGs) are sets of patients or users who have similar health care needs and who are likely to have similar outcomes (given the same packages of care).

There are obviously many differences between services for people with learning disabilities and 'mainstream' acute health care interventions. However, a pilot study by Pendaries (1997) showed that it was possible to build 'resource groups' which could offer a useful degree of cost prediction in this area, based on individuals' levels of disability and the presence or absence of challenging behaviour. Recently, this approach was further explored, using a survey of more than 2,000 adults with learning disabilities (Comas-Herrera et al., 2001). The feasibility of the approach was established: using cluster analysis, nine benefit groups were created that were meaningful from a practitioner's perspective and 96 resource groups that were coherent in terms of likely care packages.

8.5 Resource inputs

Compared to what we found when looking at the evidence in relation to services for older people (chapter 4), there is relatively little research or policy commentary on the (paid) staffing of services for people with learning disabilities, and not a great deal on family carers.

We first look at paid staff and then at family and other unpaid carers. We shall distil the evidence into two relatively brief subsections.

Staff numbers and problems

The 2001 White Paper estimated that 'There may be as many as 83000 people in the learning disability workforce (33000 in local councils, 30000 in the voluntary and independent sectors, 20000 in the NHS)' (Secretary of State for Health 2001 p.96). Three-quarters of these staff were thought to be unqualified, and problems were noted with respect to recruitment and retention, low status, few training opportunities or recognised qualifications, little workforce planning and variable involvement of service users and carers in training and planning. There was also a need to build confidence in multi-professional, multi-agency team working and greater cultural competence, and for

people working in social security, employment, housing, education, criminal justice and mainstream health care services to develop a better understanding of the needs of people with learning disabilities.

Not surprisingly, these same problems emerged from the SSI inspections of nine local authorities that same year:

On average, 25 per cent of the workforce involved with people with learning disabilities was qualified. Recruitment and retention of care managers, nurses, occupational therapists and other allied health professionals was a problem, particularly in London and the South East but increasingly in other parts of the country. Service users and carers reported that they liked the continuity offered by a named social worker or key worker they had known for some time. The use of agency workers, while necessary to cover vacancies, was not the preferred option. People also liked their care worker to be knowledgeable about learning disabilities. In councils where assessment and care management was organised on a generic basis, it was not always possible to offer this specialised service. Integrated team working should provide the possibility to offer a more specialised service (Cope 2003 p.6).

And the Learning Disability Task Force report (2004) set out what these problems can mean for service users:

We know there are not enough staff working in learning disability services, this includes support staff and care managers. This is stopping many people with learning disabilities from having choices, rights, independence and inclusion. The Task Force wants more to be done to make jobs working with people with learning disabilities something that more people want to do. We believe more work needs to be done to help services find and keep staff. We need to make sure staff feel valued, supported and well managed (LDTF 2004 p.57).

As we review here, there is supportive evidence from the research literature (although we certainly cannot claim to have covered the evidence comprehensively).

Staff training

Learning disability services have long been hampered by low proportions of trained staff. Workforce development strategies were set out in the 2001 White Paper, and a new Awards Framework introduced 'to provide a recognised route to qualification and

carer progression for care workers in learning disability services' (p.98). User and carer involvement in training and development was urged, initiatives launched to enhance professional and managerial leadership, and jointly developed local workforce plans required. The Department of Health (2003e) annual report reviews these and other initiatives taken to train staff for working with people with learning disabilities. The report notes, helpfully, that 'some councils are doing really well, but some have a lot more to do'. Mansell et al (2002) similarly argued that the training needs of residential staff should be addressed, noting the importance of preparing staff to work with people who have a range of needs.

In another paper, Mansell et al (2002a) note that the move from a hospital-based to a community-based system of care brought greater fragmentation, with small homes in a variety of organisations on many sites, and a reduced impact of specialised training as nurse training in hospital was not replaced by training for residential staff (Ward 1999; DH, 2002). One effect is for unqualified staff to find themselves less likely to have trained staff to lead them.

Recruitment and retention

High rates of staff turnover have bedevilled learning disability services in many parts of the country, linked to staff stress and low morale. A few studies offer particularly useful evidence on the challenges to be faced.

Felce et al (1993) explored the characteristics and turnover of direct care staff in thirteen houses for people with learning disabilities, based on data collected in the mid/late 1980s. Previous small studies suggest annual turnover rates of between 7 per cent and 54 per cent compared to rates for hospital-based nurses of between 14 per cent and 21 per cent. Earlier research, reviewed by Felce and his colleagues, has also shown that turnover rates can be high despite the strong motivation, positive attitudes and commitment of staff. Varying results have been found in relation to facility size, pay levels, job satisfaction and resident characteristics. In these studies, interactions with staff were often cited as the best part of the job but staff dissatisfaction and turnover have been found to be associated with extensive contact with residents, perceived lack of progress by residents and challenging behaviour.

The workforce in this study was predominantly female, mostly aged under 50. Four-fifths of the staff had previous caring experience but fewer than a third were qualified. The average turnover rate was less than 10 per cent in five houses; 11-25 per cent in four houses; and 35-48 per cent in the other four houses. Most houses, however, had retained more than half their original staff and most staff had been in post at least three years. Half of the 26 staff giving reasons for leaving cited dissatisfaction with the job, service standards, poor managerial or peer support, and pay or working conditions.

These data support the notion that staff turnover is a permanent feature of staffed housing services for people with learning disabilities and although much can be done by managers to improve some employment circumstances, poor pay and working conditions may be beyond their control. Staff development will also persist and provide a more positive reason for staff turnover. In one of the earliest studies in this area, Allen et al (1990) had suggested that staff in their middle age, particularly women with children, tend to be the most stable group, albeit more likely to require part-time work. Overall, the implication of the evidence to date is that managers need to build in good support to reduce turnover but also time and money to recruit and train new members of staff.

Blumenthal et al (1998) explored the levels of stress and insecurity among residential nursing staff in the NHS (six homes) and a voluntary organisation (five homes), focusing on role clarity, perception of the organisation and burnout. There were no differences between the services in role clarity. Compared to staff in the voluntary sector homes, NHS Trust staff were more likely to say the Trust did not listen to their views, that residents did not have a say in the way their lives were run, that the organisation had unrealistic expectations of staff, and that they were expected to undertake work that was unnecessary. NHS staff also scored more highly on a measure of emotional exhaustion, but scores for personal accomplishment and depersonalisation were similar between the sectors. Burnout was found to be associated with both lack of role clarity and poor perception of the organisation. There were differences between homes on the emotional exhaustion measure but only in the voluntary sector were there differences between the homes on the measures of depersonalisation and personal accomplishment. 'It may be that differences between the organisations are due to the greater autonomy of the charity to make and carry out decisions, whereas the NHS context is more restrictive in this respect' (p.416). The authors suggest that the NHS seek to learn from the voluntary organisation, given the lower levels of stress and more positive attitudes to the organisation in the latter.

Hatton et al (1999) used data from a survey of 450 staff to explore issues around perceptions of real and ideal organisation culture. Ideal organisational cultures were noted to be high in rewarding staff, being tolerant and staff-oriented, fostering social relationships, and low in demands on staff. Paying attention to organisational culture may result in wide-ranging improvements in staff morale, in turn having an impact on users through increasing staff motivation. In another paper from this study, Hatton et al (1999a) found that almost one third of staff working in services for people with learning disabilities reported high levels of distress indicative of mental health problems, a rate that is higher than that found in studies of NHS staff, employed adults or adults generally in the UK.

In two other papers, Hatton et al (2001, 2001a) examined the factors directly and indirectly associated with an intention to leave an organisation and actual job search,

and then the factors associated with staff stress and work satisfaction. The first paper starts with a review of US and UK literature, suggesting that high staff turnover is associated with staff characteristics (younger staff, higher education, shorter tenure), lower income or less satisfaction with income, a mismatch between expectations and the actual job, a lack of commitment to the organisation or the general type of work, a lack of support from other staff, the availability of alternative employment, high job stress, and low job satisfaction. To design effective strategies to reduce staff turnover it is important to know which of these is the most important.

Five services participated in the empirical part of this study: on average, staff were aged in their late 30s, mostly female, with almost half the sample having dependants. All but 4 per cent were white and 75 per cent were married. Only 10 per cent of residential staff were qualified. No significant differences in intention to leave were found across job titles, nor in whether they were looking for another job. Four composite variables were associated with an intention to leave: lower work satisfaction; higher job strain; younger age; easier subjective labour conditions. The factors associated with searching for another job were: lower job satisfaction, higher job strain and easier subjective labour conditions. Feeling trapped in a poor organisation is a more important factor in staff to turnover than not being committed to that organisation. The authors suggest that organisations may be able to reduce staff turnover by recruiting and retaining older staff (possibly through the provision of more flexible working practices), provide additional training to younger staff, ensure staff have realistic expectations of the job and that they are committed to this type of work. Given the importance of the wider employment market, organisations should ensure pay and conditions compare favourably with alternatives.

Hatton et al (2001a) explored factors directly and indirectly associated with staff general distress, job strain and work satisfaction. General distress was significantly associated with wishful thinking, stress linked to work-home conflict and role ambiguity. Job strain was significantly associated with wishful thinking, stress linked to a lack of staff support, 'alienative' commitment, role ambiguity, stressors linked to low job status, and working longer contracted hours. Work satisfaction was significantly associated with stress linked to a lack of staff support, support from supervisors, influence over work decisions, 'alienative' commitment, support from colleagues, and older staff age. In discussing their results, Hatton et al emphasise the distinct nature and contribution of general distress, job strain and work satisfaction. The strong impacts of organisational variables on staff stress and well-being suggest high staff stress and low morale are not inevitable features of working with people with learning disabilities.

The stresses experienced by managers have not been studied very often. Rose et al (2002) collected data from 57 managers of community homes and 49 direct care staff working in ten of these same homes. Managers reported feeling significantly more pressured than direct care staff, and had higher reported levels of anxiety. On the other

hand, managers reported higher levels of job satisfaction. Managers reported higher ratings on all sources of stress than did carers (career, organisational issues, relationships, responsibility, work/home interface, workload and role clarity) but the two groups had similar levels of support both inside and outside work, except that managers felt they got *less* support from their line managers.

Specialist teams

The organisation of care along specialist rather than generic lines is generally seen as preferable, and there have been multi-professional community teams for quite some years. *Facing the Facts*, the Department of Health (2000a) review of social and health care services for people with learning disabilities, noted some positive developments.

Allen (1998) found that the development of community support teams had no impact on the rate of hospital admissions by people with learning disabilities overall, but did reduce a number of long-stay admissions. The introduction of specialist services appeared to be associated with reductions in rates of both long- and short-term admissions. The analyses are quite limited, simply looking at changes through time within one Welsh locality, and it is not clear whether admission to hospital was replaced by admission to other services for whom data were not available (such as facilities in the private sector or outside the catchment area).

McCray (2003) discusses models for inter-professional practice in the learning disability field.

Carers

It is again helpful to start with a summary of recent reports from the Department of Health, and then to turn to the research literature.

Recent views from the centre

The 2001 White Paper had noted 'Carers can feel under-valued by public services, lacking the right information and enough support to meet their lifelong caring responsibilities' (p.19). A key policy objective was therefore 'to increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively'.

The 2001 SSI inspections of learning disability social care services point clearly to the challenges faced by and in relation to family and other unpaid carers:

The majority of carers were satisfied with services, once they had been set up. Key areas for development were:

- a substantial proportion of carers did not know about the complaints system, of their rights to a separate assessment, nor of their right of access to their files;
- there was a need for more short-term breaks;
- most councils did not have a database of carers aged over 70 years;
- more sensitive provision was needed for carers from minority ethnic groups;
- when modernising services, it was crucial to involve carers from the beginning and make efforts to win hearts and minds (Cope 2003 p.4).

Only one-third of carers in the nine inspected authorities in 2001 had a named care manager (Cope 2003).

The concerns of family carers are summarised well by the Learning Disability Task Force:

Some families are saying that things are getting worse. Families worry about what is going to happen in the future, especially older family carers ... Each local authority needs better information about people with learning disabilities and families ... There are not enough services, people with learning disabilities and families need breaks, services for people in the day time and housing' (Learning Disability Task Force 2004 pp.26-27).

The annual reports from the Department of Health (2003e, 2004b) each include a chapter on supporting carers, and providing some indications of action taken to address carers' needs. The establishment of the Learning Disability Helpline in December 2001 had provided useful information to 6000 people by October 2002, 27 per cent of whom were carers. Carer grants, established in 1999, paid for respite breaks, and an extra £140 million was provided for this carer service over the three-year period to 2001/02. The grant continues and was planned to double to £185 million by 2005/06. The 2003 report also noted some improvements in supporting carers from BME communities, and providing plans for older carers (although the proportion covered in this way was only 50 per cent in 2002/03). The 2004 report continues the emphasis on supporting parents and carers. A variety of initiatives are described, including networks and some additional funding.

Findings from research

The research literature substantiates and develops these summary observations from the centre. Here we pick out a few studies.

The cross-sectional study by McGrowther et al (1996) gives a good summary of who these carers are and what tasks they undertake, as well as the help that they feel they need. They collected information from 982 carers of people on the Leicestershire Learning Disabilities Register. Most carers were aged 40 or over and 17 per cent aged over 70 years; 89 per cent were female, commonly mothers. Over 90 per cent of carers provided help with paperwork, providing meals and other practical help. Over 80 per cent took people with learning disabilities on outings and over 60 per cent provided company. Two-thirds regularly provided personal care or supervised medication. A quarter provided physical help. Two-thirds were happy to provide care, 23 per cent merely resigned and only 17 per cent expressed dissatisfaction. A lot of stress was reported by 22 per cent carers. Female carers of working age reported 40 per cent more limiting health disorders compared to general population. Depression, 'bad nerves' and musculo-skeletal problems were significantly more likely to be reported. The study shows clearly that carers are a high-risk group who would value long-term health and social care support and regular surveillance from GP as well as focused interventions directed at personal and environmental coping strategies.

In a subsequent study built again on the Leicester Learning Disabilities Register, McGrowther et al (2002) collected information from the carers of over 2500 South Asian and white adults. Only 64 per cent of South Asian carers knew about respite care, compared to 89 per cent of white carers. Similar levels of carer stress, health status, and social support were reported between the two groups.

This theme was also examined by Hatton et al (1998), who looked at the family circumstances, service supports and levels of stress experienced by 54 South Asian carers of people with learning disabilities in two metropolitan boroughs. Asian families with a member with learning disabilities tend to have circumstances of material disadvantage, with 62 per cent in this sample living in moderately or severely inadequate housing and 46 per cent reporting great difficulty in paying bills. Carers also report very high levels of stress, with 78 per cent of carers scoring above the cut-off on the Malaise Inventory. Apart from day services, awareness of other forms of support was very low, and was found to be associated with ability to speak and write English. The number of services used by someone with learning disability was found not to be closely associated with severity of learning disability, but was linked with the amount of time the person could be left unsupervised, higher weekly income and the longer the time the carer had spent in the UK. Stress was higher for carers with lower weekly household incomes and where there were more people with learning disabilities in the household. Only 17 per cent of carers were satisfied with the services they received and

35 per cent were dissatisfied, with 61 per cent reporting that they had little confidence in the ability of services to help in times in crisis. Carers would like better communication between themselves and services, improvement in the cultural sensitivity of services, and more flexible services.

Do respite care services help? Flynn et al (1996) looked at the development of respite services for adults with learning disabilities in England, and particularly the contributions made in this area by social services departments. The most common form of respite care was in residential units, but social care staff and service users had different views about what constituted a valued respite service. The most impressive looking services shared a number of characteristics: they involved people with disabilities in the planning of services, they put emphasis on the development of befriending services, they created opportunities in a variety of areas, they offered training to improve the quality of services, and they promoted choice. However, a number of the services were described as being in a 'fragile financial position', leaving them uncertain as to their future. Cost information is provided on the services, but the report notes that there is no cost-effectiveness evidence regarding different forms of respite services. There was also no evidence on the number of respite places available in England.

There have been a number of studies of family carers of children with learning disabilities. Emerson et al (2004) summarised much of the earlier literature:

Over the past three decades, a substantial body of research has explored associations between a wide array of inputs, processes and outcomes relevant to the situation of families bringing up a child with intellectual disabilities. This research has consistently reported that: (i) a significant minority of family carers (primarily mothers) of children with intellectual disabilities experience high levels of psychological distress and (ii) the prevalence of psychological distress among family carers of children with intellectual disabilities is greater than that found among family carers of children who do not have disabilities. While the reported levels of psychological distress are of social significance in and of themselves, they are also of concern as a result of the well-documented association between maternal psychological distress and 'dysfunctional' parenting behaviours and practices which may have a detrimental effect on child development (Emerson et al 2004 p.77).

Emerson et al go on to cite evidence from previous research on the determinants of mental distress: challenging behaviour, gender, communication ability, difficulty of caregiving, coping strategies employed by parents, parental characteristics, the nature of support available to parents, ethnicity and culture, and macroeconomic structures. The link between poverty and health is noted as significant because many families with a disabled child find themselves in straitened financial circumstances (because of the

restrictions imposed on ability to seek paid work).

In their own empirical study, Emerson and colleagues found that 47 per cent of primary carers of children and adolescents with learning disabilities scored above the GHQ threshold for psychological distress. The greater the emotional and behavioural needs of the child, the higher the probability of exceeding the threshold. South Asian ethnicity was significantly associated with distress (70 per cent of primary carers in this community), perhaps mediated by socio-economic deprivation.

Grant et al (2003) argue that families may need different types and levels of support over time as the course of learning disability progresses and the type of care needed by individuals also changes. This is linked to parental recognition that these needs are changing, alongside the changing care-giving skills and abilities of parents themselves.

Overall, and returning to the summary of inspections

More needed to be done to win the 'hearts and minds' of carers if service users were to take advantage of new inclusive services. Carers often needed to see evidence that new services worked before they could have confidence that changes to existing services were in users' best interests (Cope, 2003).

8.6 Services

General trends, patterns and aims

There have been many improvements in services for people with learning disabilities over recent years, but many deficiencies and gaps remain. The 2001 White Paper, *Valuing People*, was very clear on this point.

The expansion of and improvement in some services has undoubtedly led to better outcomes for many people with learning disabilities. However, this does not mean services fully meet their needs. Research has consistently shown variable quality of community-based services; concerns about shortfalls of provision in particular services; and varying degrees of commitment to learning disability services by local authorities and health authorities (p.18).

The White Paper noted that 'great variation across the country in terms of availability and coverage of services, as well as quality' (p.20), and cites research and routine

statistics in support of this assertion. For instance, the number of adults receiving care in publicly supported accommodation ranged from 12.7 per 10000 adult population (aged 18-64) in one area to 59.2 in another, but even then 'few places offer real choice' (p.21). Respite care and day services also vary considerably in availability and funding across the country. Naturally, therefore, the policy objective was to improve the quality of services 'To ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value' (p.90).

In reviewing what services have been provided we structure this section as follows:

- Case management and person-centred planning
- Family support
- Supported accommodation (including hospital)
- Vocational, educational and leisure
- Targeting
- Quality assurance

There is inevitably a risk of some overlap between this section on services and our broad discussion of needs in section 8.3.

Case management and person-centred planning

Central to the 1990 legislation and its associated guidance was the reconfiguration of services and decision making so that services responded to assessed needs rather than shoehorning people into predetermined service systems. Care management was the vehicle given most prominence to ensure that social care became more needs-driven, but in the learning disabilities field there is quite a long history of related but certainly not identical processes such as individual service planning (ISP), individual care planning (ICP), individual programme planning (IPP), lifestyle planning and person-centred planning (PCP). The last of these has an absolutely central role to play in the new arrangements announced in *Valuing People*. There is no shortage of good intentions to pave the way forward, but in modern parlance we have an actual or potential *implementation gap*.

Care management

The care management aims of the 1989 White Paper and the 1990 Act applied with equal force to people with learning disabilities as to older people, although much less attention has been paid to the former. Cambridge (1999) reviews much of the experience, noting how care management was functionally redefined over the 1990s in response to the developing mixed economy of care. He suggests a number of dimensions for reviewing the implementation and effectiveness of care management in this area, including organisational structures, service co-ordination, targeting on needs, information systems, transaction costs, service models, inter-agency and inter-professional working, relations with local multi-agency learning disability support teams, assessment, and how to hear and act upon the preferences of people with learning disabilities. There appears to be relatively little evidence on most of these dimensions, although smaller caseloads of 20-30 people appear to increase the chances of a more effective service. (See also the evaluative evidence on care management from the twelve-year follow-up of the Care in the Community pilot projects in Cambridge et al 2004. A number of different models of care management are described.)

Care management is an important part of the system of services for people with learning disabilities, described in the White Paper as 'the formal mechanism for linking individuals with public services. Its systems must be responsive to person-centred planning, and have the capacity to deliver the kinds of individualised services likely to emerge from the process' (Secretary of State for Health 2001 p.50). Care management processes need to link with Connexions, health action plans, housing plans and communication plans, as well as of course, person-centred approaches. But care management itself may not deliver person-centred planning, which is one of the reasons why the 2001 White Paper emphasises the importance of the latter. 'Some people receiving publicly funded services have problems accessing the care management they need. This confusing and inconsistent situation is unacceptable' (Secretary of State for Health 2001 p.49).

Progress with implementation

Not surprisingly, the SSI inspections in 2001 found the same inconsistencies and duplication in relation to care management that were noted in the White Paper. Eligibility criteria were often too complex for staff to understand, let alone service users and their carers. Assessments were not always carried out by specialist learning disability care managers. Other shortfalls were identified. Cognisant of the aims in the White paper, the summary report thus set out expectations that service users should be able to hold. One concerned the planning of their care:

Service users should ideally have a person-centred plan, which is reviewed by a multi-disciplinary team in partnership with the person at regular intervals. Council service plans should be more holistic and less provider-driven than in the past. People with learning disabilities should be fully involved in decisions making that affects their lives (Cope 2003 p.18).

Although it was early days, the inspections found a widespread

commitment to adopt a person-centred planning approach. However, the practice of closing cases when a package of care had been set up was the norm; this meant that around two-thirds of service users and their families did not have a named key worker to contact when circumstances changed. Often a new referral had to be made, which people said they found irksome and frustrating (Cope 2003 p.3).

A couple of years later the Department of Health (2003e) annual report noted that most authorities had plans to introduce person-centred approaches to service provision.

Person-centred planning and the *Valuing People* agenda

Person centred planning (PCP), under the slightly different guise of individual service planning, developed around 30 years ago in the USA, 'possibly borrowed from the concept of *individual education plans* mandated by special education legislation in the USA in the mid-1970s' (Parmenter 2004 p.25). Although the approach has been employed for quite some time, it was generally only available to a minority of users. Individual programme systems were often established but not sustained, and there were wide variations between authorities (Learning Disability Advisory Group 2001; McGrath 1991). The advent of care management was seen in some quarters as a return to resource planning and a distraction from the needs-based planning that characterized individual programming (when it happened, of course) (Todd et al 2000).

Person-centred planning is a key component of the current policy framework. Mansell and Beadle-Brown (2004) set out the main differences between PCP, ISP and other variants. As they explain, PCP takes an individualised approach to assessing people with learning disabilities and organising what should be done, sharing this focus with other mechanisms such as individual programme plans, individual service plans and case management methods. However, PCP also aims to consider the users' aspirations and abilities as expressed by themselves or their advocate, and aims to mobilise the person's family and wider social network as well as formal care resources. PCP also makes the link between providing services and achieving goals rather than limiting goals to what services can provide.

Most of a recent issue (March 2004) of the *Journal of Applied Research on Intellectual Disabilities* was devoted to person-centred planning. It features a very helpful debate on what PCP comprises, whether there is any evidence that is effective and what needs to be done to ensure that this plank of national policy moves learning disability services forward. We will not attempt to detail the six papers but will pull out relevant elements for this chapter.

Mansell and Beadle-Brown point that the wide-scale introduction of PCP will be complex and challenging, in part due to the communication and other needs of people with learning disabilities, their high level of social isolation, and their small social networks. They also suggest that there is also a 'general difficulty in modern society of developing and sustaining relationships of the kind required ... In practice it is usually the family, and overwhelmingly women, who undertake the role of helping people with substantial needs (2004 p.3).

They question whether, given a history of individualised planning dating back certainly to the mid-1970s, there is evidence to suggest that this national policy initiative will meet with any success. They refer to the systematic review by Rudkin and Rowe (1999) that found five studies of life-style planning (involving a total of only 108 people), none of them large enough to show statistically significant outcome differences for people receiving PCP. Studies of other forms of individualised planning suggest that it reaches only a minority of people with learning disabilities, and that too often it is only a paper exercise with goals rarely materialising as a programme of support. They also argue that evidence indicates that 'individual plans are not well connected to the real lives of people using services' (p.4), with goals set in the absence of service users or their carers and not written in measurable terms.

A suggestion often found in the care management literature is that the financial systems are not sophisticated enough to support individualised planning. This, alongside the absence of a legal mandate for PCP, may impede the adequate implementation of person-centred approaches. Mansell and Beadle-Brown note that in this environment there is a risk that service agencies will redefine activities they have funded in the past as part of mobilising informal supports (p.5). For those people living in staffed accommodation, lack of training and skill shortages among staff may further impede the implementation of PCP as means to change users' lives.

Mansell and Beadle-Brown therefore conclude that the widespread introduction of PCP will require changes in the balance of power between individual service users and social care agencies as to who determines goals and implements plans. This may need PCPs to be given legal weight, giving service users entitlement to a particular level of resources through changes in both social security benefits and social services funding decisions (p.6), making more use of direct payments and user-controlled trusts, a new policy expectation that PCPs would be resourced and achieved, and performance

management focusing on quality of plans rather than numbers of plans made. In other words, we have another potential 'implementation gap' that will take a lot of effort to bridge.

Four responses to the paper by Mansell and Beadle-Brown (2004) are published. O'Brien (2004) shares their concerns, pointing to the danger of under-funding of the arrangements necessary for a system such as PCP to be effective. He also worries that PCP could become 'an activity trap, displacing attention and funds from the hard work of assuring that people receive day-to-day competent assistance and from the demanding work of realising opportunities for inclusion' (p.11). He has a more optimistic outlook than Mansell and Beadle-Brown on what the 2001 White Paper is proposing and what it might achieve, but his final section (entitled 'Too much optimism?') is also cautious:

The probability of failure increases if cynicism or pessimism leads people to hold back either their commitment to action or their interests in reflecting on results. There is neither need nor justification to look at person-centred planning through rose-coloured glasses. There is good reason to look with clear eyes at the possibilities for significantly greater measure of choice and inclusion and to make an energetic commitment to the hard work of making those possibilities real at whatever scale the local and national environment can support. Person-centred planning has modest but important role to play in steering those changes, so it deserves both committed action and careful scrutiny (O'Brien 2004 p.15).

Towell and Sanderson (2004) comment on, and generally defend, the proposals in *Valuing People*. They note their belief 'that any major programme of social change needs some creative tension between hope and scepticism, although we are tempted to think that [Mansell and Beadle-Brown's] critique allows the latter to get the upper hand!' (p.19). They argue that person-centred planning cannot be assessed separately, but is part of a more holistic approach.

Person-centred planning functions as much more than an advanced collection of individual planning processes and tools. Policy emphasis on person-centred planning strengthens the claims that people with intellectual disabilities want access to opportunities and support, which reflect their individual aspirations. Wider informal participation in the problem solving networks 'circles of support' broadens the base for creating innovative solutions and also the social support in facing disappointments. On a larger scale, person-centred planning is a key vehicle for operationalising in everyday practice the abstract principles upon which *Valuing People* is based (Towell and Sanderson 2004 p.20).

Emerson and Stancliffe's (2004) response to Mansell and Beadle-Brown is more upbeat in its interpretation of the existing evidence, but shares their concern

that system-wide adoption of PCP will be characterised by over-zealous 'selling' of the purported benefits without sufficient attention to the difficulties and without the necessary changes to system architecture to ensure that those involved in PCP have the authority or resources to achieve the plan's goals. If so, PCP will become another fad, and service users and their families will become even more discouraged, disheartened and alienated by a system characterised by rhetoric rather than meaningful action (p.25).

Felce (2004) reminds us that PCP is not only central to the objectives of *Valuing People*, but is also recommended as 'an essential user-orientated planning process in Wales ... and Scotland' (p.27). He expresses concern that PCP is promoted as a mechanism for individual planning, but is also seen as the 'data generator for strategic planning'. He goes on to express concern that government has retreated from the setting of targets in terms of service provision until the needs at an individual level have been determined. This 'is a serious backwards step. Policy is weaker for the absence of indicative provision targets' (p.27). He does, however, share Mansell and Beadle-Brown's view that the evidence base for PCP is rather weak. He also feels that the differences between PCP and the variety of earlier individual planning approaches have been exaggerated, but if correct the evidence base is all the thinner.

Policy-makers, senior managers and leaders in our field are embarking on PCP not out of evidence that people receive better support and live enhanced lives as a result, but because they have convinced themselves, or been convinced by persuasive campaigners, that PCP is a logical and necessary approach to knowing people well enough so as to be able to make support arrangements that meet their individual requirements and take account of their preferences and lifestyle choices. I find it difficult to contest this logic. ... For me, the relevant question is not whether PCP has the potential to improve people's lives but whether policy has identified the conditions under which its widespread implementation would be possible without degradation of the process and its impact (pp.27-28).

He criticises the lack of projection of the resource consequences of introducing PCP ('That it may require resources does not seem to be part of its sales pitch' p.28). This leads him to argue that PCP cannot be widely implemented in the short or medium term, but must be a long-term process, alongside the restructuring of other service arrangements and commissioning processes. For this reason, he is uncomfortable with the view that PCP is a driver of strategic change.

In reflecting on these comments, Mansell and Beadle-Brown (2004a) restate their three main points. First, they see the task envisaged in the 2001 White Paper as very ambitious. Second, they question whether individual plans of the kind envisaged are actually feasible or effective in changing the lives of people with learning disabilities. Third, they argue 'that budgetary control mechanisms are used to undermine the individualised, tailored nature of planning and, therefore, the introduction of a new model of planning will not, in itself, be likely to change the experience of service users' (p.31). They do not agree with Towell and Sanderson that it is not possible to assess the impact of PCP separately, because a component of a holistic approach that 'is expensive, time consuming and has limited empirical support' surely needs careful evaluation. They also express concern that the evidence base, much as has been the experience with the implementation of care management in relation to the support of older people, describes what can be achieved in an ideal world, not in the realities of everyday practice away from the goldfish bowl of pilot sites. The experience with care management for older people, with still very uneven implementation of the evidence-based model, is salutary. This, combined with concerns about the transaction costs of implementing a PCP-structured system, leaves them still sceptical about this important plank of government policy.

Assessment

A good illustration of the limitations of current data collections on learning disability services is that we can say little or nothing about the implementation of PCP or the numbers of people supported through care management. We can however see how many people have had assessments and what delays there have been in assessing needs. The overall picture is not good: a minority of people with learning disabilities receive assessments, and there are often long delays.

Between 28,000 and 29,000 learning disability clients had a completed assessment in England over the period 2000/01 to 2002/03 (see figure 8.12). Despite this relative stability in terms of overall number of cases, figure 8.12 shows a significant increase in the number of adult clients with completed assessments and a small reduction in the number of older clients. It is difficult to say whether this evidence suggests changes in the targeting of resources or reflects changes in the classification of cases between user groups. Overall, 90 per cent of the 29,000 clients with completed assessments classified as people with a 'learning disability' in 2002/03 were aged 18-64 years.

Figure 8.13 shows almost no changes in the distribution of anticipated sequel to assessments in England for the period 2000/01 to 2002/03. In around 24 per cent of cases, no new services were offered or intended following assessment, with around 4 per cent cases declining the services offered following assessment.

Figure 8.14 shows a very significant variation in the number of assessments for people with learning disabilities in Wales in the period 1994 to 2001. This volatility appears to be related to significant changes through time in the number of non-residential care packages arranged. In spite of their predominance in terms of proportional spending, figure 8.14 shows how residential based packages of care represent only a minority of the overall number of care packages arranged. The majority of placements in institutions are targeted to nursing homes.

Figures 8.15 and 8.16 show respectively the length of time for learning disability clients from first contact to completed assessment, and from first contact to first service, by age and for the period 2000/01 to 2002/03. Over this period, the data summarised in figure 8.15 suggest a slight deterioration in the time taken by services to complete assessments for clients aged 18-64, so that whereas in 2000/01 around 72 per cent of cases had their assessment completed within twelve weeks, this figure dropped to around 64 per cent of cases in 2002/03. Overall, time to completion of assessments is shorter for older clients.

In 2002/03, about 18 per cent of new clients received a completed assessment on the contact day (that is, on the day of first contact) or the following day, 33 per cent received a completed assessment within two weeks while 20 per cent waited more than 6 months.

Figure 8.16 also indicates shorter lengths of time from first contact to first service for older clients. In 2002/03, 19 per cent of clients received their first service on the contact day or the following day, 29 per cent received their first service within one week and 36 per cent received their first service within two weeks.

In many councils there was a backlog of reviews, with some service users in expensive residential placements some distance from home not having received a council or health-organised review for years. Councils had found it beneficial to look at the mix of skills in assessment and care management teams, leaving more complex work for qualified social workers and community nurses (Cope 2003 p.4).

The numbers of people in England receiving services following assessment, by service type and age, over a three-year period are given in figure 8.17. There was an increase in the number of service users over this short period, mostly an increase in the number of independent sector residential care placements. In 2002/03, over 127,000 adults with learning disabilities received services in England, 32 per cent of whom were placed in a residential or nursing care facility. Figure 8.18 provides a breakdown of care packages for people with learning disabilities in Wales in 2001. Around 78 per cent of service users lived in the community, a higher percentage than in England. In Northern Ireland, the number of care packages in effect on 31 March has grown substantially over the

past five years (figure 8.19). There has been a sharp increase in the number of residential and nursing home care packages. In 2002/03, there were 1421 residential or nursing home care packages in Northern Ireland, around 2.5 times the number in 1998/99. (Note that, in Northern Ireland, the term 'care package' is used to relate to the provision of services following an assessment by intensive case management. As a result, care packages exclude low intensity service packages.)

Family support

As we noted earlier when discussing the roles of family and other carers, and the pressures they face, there are pressing needs for a range of respite and other family support services. Many carers complain of difficulties in accessing relevant information. This is particularly a problem for carers from some minority ethnic communities. Carers of adults with learning disabilities are often socially isolated (Emerson et al 2001). As the Learning Disability Advisory Group (2001) describe, the All Wales Strategy gave high priority to the development of services such as respite care and family aide to address these multiple needs of family carers. With the growing emphasis on accommodating people with learning disabilities in their own homes, pressures on families may lessen, although such a situation is transparently some way into the future.

The LDTF (2004) report notes that:

Poverty is a big problem for many families, especially families supporting people with high support needs. ... Benefits do not always cover extra costs for things like special equipment, accessible transport or childcare for parents who need to work. Many families say that they are living in poor housing and they are finding it very hard to get help with adaptations and equipment (p.47).

There is clearly confusion in the minds of many day centre and other staff about benefit entitlements. The Task Force also advocates wider accessibility to benefits and support arrangements for people with learning disabilities which are currently often only offered to people with other disabilities.

Supported accommodation

The pattern of accommodation for people with learning disabilities has changed markedly over the last three decades. First was the movement out of the 'mental handicap' hospitals (faster than the equivalent programmes of hospital rundown for people with mental health problems and older people), followed by recognition that much of the replacement community provision was almost as institutional, often being

isolated, disempowering, regimented and poor quality. What we see today is considerable emphasis on choice and control, and a commitment to develop more mainstream, 'ordinary' housing options: 'Too many people with learning disabilities and their families still lead lives apart, with limited opportunities and poor life chances' (Secretary of State for Health 2001 p.17). The policy emphasis today, therefore, is to 'open up mainstream services, not create further separate specialist services'.

In this section on supported accommodation we therefore look in turn at the overall balance of care, and then at the three main components: hospital provision, staffed community accommodation, and supported living and ordinary housing.

The balance of care

Kavanagh and Opit (1998) analysed data from the nationally representative epidemiological surveys of disability carried out by the OPCS in the mid 1980s. These surveys have the advantages of scale (100,000 households received the screening questionnaire, for example, and there were similarly grand approaches to the collection of data from people in 'institutions'), national coverage, representative samples, and of being able to identify disabilities and needs for people who are not necessarily in contact with services. In an earlier section we reported the cost estimates by Kavanagh and Opit (1998) based on their uprating of the prevalence and service use patterns from the survey data of the 1980s to the conditions and prices pertaining to 1994. For the present purposes it is more helpful to look at the original service use calculations for 1986. These show that there were 165,388 adults (defined as aged 16 or over in this study) with learning disabilities in Britain, distributed by place of residence as follows:

Private households	105596	(64 %)
NHS hospitals and homes	40943	(25 %)
Local authority residential homes	11533	(7 %)
Voluntary care homes	3446	(2 %)
Private care homes	3851	(2 %)

The 2001 White Paper contrasted service profiles over a longer period in 1969 (as reported in the 1971 White Paper) and 2000:

- 58850 places in NHS hospitals and units in 1969, compared to approximately 1000 in 2000, half of which were in NHS-managed residential accommodation
- 4900 places in residential care homes in 1969, compared to 54300 places in 2000
- 24500 places in adult training centres in 1969, compared to approximately 84000 adults receiving community-based services in 2000, of whom 49680 attended social care day services and 6630 using NHS day care facilities.

A paper by Harker (2003) on the Valuing People of the Department of Health website estimates the following balance of care, although the numbers given do not appear to be fully consistent with the Department's own statistical data:

Adults living in parental home	90000	(49 %)
Residential care homes	60000	(32 %)
Supported housing (shared and s/c)	22000	(12 %)
Adult placement	5000	(3 %)
NHS care	7000	(4 %)
Long-stay hospital	1000	(<1 %)

Over the eleven-year period from 1990/91 to 2000/01 there have been marked changes in the balance of accommodation. Full details are given in a Department of Health Memorandum for the House of Commons Select Committee on Health (October 2002) and we simply summarise the main contrasts below:

Average daily no. of beds/places	1990/01	1995/96	2000/01
NHS facilities	23050	12310	9640
Private nursing homes, hospitals	1580	3250	3710
Staffed residential homes	30470	38180	43660

(of which private or voluntary)	(18360)	(28840)	(37030)
Small registered homes	N/A	5700	9740
Total available places	55090	59430	66750

Although it is sometimes difficult to reconcile figures coming from different Department of Health publications and reports (about which more later), it seems clear that (a) total staffed provision has grown, (b) the NHS contribution to the total has waned, (c) the private and voluntary sector market shares have grown considerably, and (d) there has been growth in provision in small registered homes. We have excluded places for children from these figures.

Hospital accommodation

As we have just seen, the number of people resident in long-stay NHS 'mental handicap' hospitals in England reduced from over 58,000 in 1969 to a little over 1,500 in 2000 (Department of Health, 2001). We assume this latter number is correct, although it does deviate somewhat from the figure supplied by the Department of Health to the House of Commons Select Committee on Health in October 2002. In their memorandum the Department tabulated figures that showed 4190 long-stay beds in NHS facilities in 2000/01, having fallen from 22140 in 1990/91. Presumably a distinction is drawn (although we have yet to find the explanation) between long-stay beds in the old 'mental handicap' hospitals and those in other forms of NHS facility, including NHS campuses. On the latter, the 2001 White Paper referred to the evaluation of Emerson et al (2000) in arguing the reconsidering the roles of the residential campuses:

Research has raised significant concerns about the quality of life enjoyed by people living in NHS residential campuses developed as a result of the contraction or closure of NHS hospitals. In the case of residential campuses and retained beds, Partnership Boards should agree a timetable for extending person-centred planning (to commence by October 2002) to all people currently living there. This will inform discussions with the person and their family to decide whether alternative community-based housing, care and support options would be in their best interests. Where they are, these alternatives should be made available. Where people wish to remain in NHS residential campuses, Partnership Boards will be expected to monitor and improve the quality of the care they receive (Secretary of State for Health 2001 p.75).

The White Paper set April 2004 as the target date by which all people in long-stay hospital beds would have moved to 'more appropriate' accommodation. That target was not hit. The 2003 annual report from the Department of Health (2003e) registered disappointment that some long-stay hospital places remained open: there were still 21 long-stay hospitals open in 2003, accommodating about 1000 people with learning disabilities. The LDTF (2004) report estimated that about 700 people with learning disabilities were still living in long-stay hospitals, many of them with high support needs. In its response, in its 2004 annual report, the Department of Health noted that it expected the final closures would occur by April 2006: 'There is a two-year delay, but it is better that people's lives don't suffer because there is a rush to close the hospitals' (Department of Health 2004b p.35). This is undoubtedly true, but critics will complain that action could presumably have been taken earlier to ensure that plans did not have to be rushed.

The Valuing People Support Team continues to help local agencies to plan the closures of hospitals. The team is now reported to be starting to help Learning Disability Partnership Boards 'plan how people can be helped to move out of NHS campuses to other housing and support' (p.35). An Extra Care Housing Fund was established in 2003, with an allocation of £87 million, including a small amount (£2 million) 'for pilot schemes to look at ways to help people with learning disabilities who had been living with their parents before but whose parents have died or become too old to look after them' (p.36). Most of the funding is allocated to support older people, including some with learning disabilities.

In Wales, there were 366 people resident in long-stay hospitals in March 2000 (Learning Disability Advisory Group 2001), with the Welsh National Assembly setting a target date of 2010 for closing all such places.

In 1975, shortly after health and social services in Northern Ireland were reorganised into an integrated single department, a strategy for health and personal social services was published, which included the aims of moving from hospital to community-based services, and the relief of overcrowding in hospitals. It was not until the regional strategy for 1987-1992 that progress was achieved, with the introduction of a 20 per cent target for reducing the numbers of people in each of the psychiatric and learning disability hospitals in Northern Ireland. Transitional funding was put in place to establish community facilities to allow the hospital discharges to be made. Progress appears to have been rather slower than in either England or Wales.

And why has this been such a dominant policy concern? A long quote from Emerson et al (1994) captures the essence of the concerns about institutions: a heady mix of economic goals, outcome expectations, civil rights concerns and a desire to extend choice and autonomy.

The last three decades have witnessed the growth of a veritable catalogue of criticisms of institutional forms of care for people with learning disabilities. Long-stay institutions have been criticised for their excessive size, the segregation of their residents from the outside world, the separation of residents from their family and friends and from the general life of the community, the poverty of their material and social environments, their low staffing levels, the absence of stimulation and of meaningful pursuits for residents, for the development of abnormal systems of care or, in some, for the degrading and, at times, abusive patterns of relationship characteristic of an institutional culture.

Over the same period, concerns regarding the predicted costs associated with continued institutional provision provided a window of opportunity for planners, managers, professionals and advocates to translate emerging ideas about alternatives into actual practice as the values and objectives which help shape services have moved away from custodial care to ones which emphasise habilitation, quality of life and normalisation, alternative models of community-based provision have begun to be articulated. These alternatives have been broadly defined by the reduced size of their settings, their location within ordinary communities, higher levels of staffing and a re-definition of staff roles to replace the emphasis on health care with aims based upon social care, enabling and support. Community-based services have sought to enable users to experience the patterns of living, learning, working and enjoying their leisure time typical for people of their age in the wider community (pp.3-4).

Residential care accommodation

The option for replacing hospital beds favoured in most localities was to open staffed residential facilities. The trends in provision can be seen from Department of Health statistics. Figures 8.20 and 8.21 depict the numbers of residential care homes and places for learning disabled adults in England over the period 1994 to 2001. Figure 8.20 indicates an almost two fold increase in the number of homes up to around 8600 homes by 2001. This trend appears to be fuelled by a rapid expansion in the number of small registered homes, from 1709 in 1994 to 4060 in 2001. In 2001, around 47 per cent of homes were categorised as small registered homes, incidentally the same proportion as private and voluntary registered homes. Local authority staffed accommodation dominated provision throughout the 1970s and 1980s, peaking at around 16900 places in 1989 and 1990, and declining in market share thereafter.

Not surprisingly, the impact of the growth in the number of small registered homes on the number of residential places is less marked (see figure 8.21). Nevertheless, the proportion of places in small registered homes in England grew between 1994 and 2001

from 8 per cent to 18 per cent, while – looking at the sector balance – the proportion in local authority homes decreased from 27 per cent to 12 per cent.

There was substantial growth in the number of residents with learning disabilities (under 65 years of age) in England supported by local authorities over the period 1994 to 2003 (Figure 8.22), with the number doubling from around 18000 to more than 36000 over the ten years. Proportionately, the vast majority of placements are now made in independent sector homes. The proportion of supported residents in local authority homes fell from 46 per cent to 12 per cent. The number of temporary admissions of local authority supported residents in England increased steadily over the period 1997-98 to 2002-03 (Figure 8.23), while there was a reduction in the number of permanent admissions.

Figure 8.24 shows an increase in the number of homes for people with learning disabilities in Wales between 1990 and 1995. Subsequently, the picture indicates a fall in the number of homes between 1997 and 2001. Proportionately, the local authority market share has fallen considerably over the period (from 76 per cent of all homes in 1990 to 17 per cent in 2001). This figure also suggests that the ratio of places to residents in independent sector homes remained constant between 1990 and 2001, whereas it fell for local authority homes, possibly suggesting an increase in occupancy rates (the figures do not take into account privately arranged placements).

In Northern Ireland, following a significant decrease in the number of premises between 1998/99 and 2000/01, the number of the residential homes had increased up to 92 by 2002/03 (figure 8.25). Despite a small fall between 1998/99 and 2002/03, the proportion of homes controlled by local authorities (or their equivalents) remained much higher in Northern Ireland than in England or Wales (by 2002-03, around 22 per cent of homes were still classified as belonging to the statutory sector). Overall, the largest provider of places for learning disability clients in Northern Ireland is the voluntary sector, whose share of the market increased to 46 per cent by 2002/03.

Residential provision may have replaced hospital provision in more than one way, as it would appear that much of today's accommodation is isolated from mainstream community life and remote from the family homes of residents (Hatton and Emerson 1996; Emerson and Hatton 1998). The 2001 SSI inspections found 'large numbers of external residential placements, often [purchased] at high cost, which had not been reviewed for years' (Cope 2003 p.22). However, local authorities were said to be aware of the problem and were also seeking to find placements 'with a view to meeting needs closer to home'. Another problem, highlighted by Thompson et al (2004), is that many (younger) adults with learning disabilities are living in generic accommodation facilities for older people. Placement had often been made not because of any change in their own needs but because of organisational changes or the ageing or death of a family carer.

Hatton and Emerson (1996) reviewed the research literature relating to residential care, focusing particularly on characteristics of facilities, their quality and their costs. We will summarise their findings in the section on outcomes and cost-effectiveness, but it is worth noting here the wide variations uncovered in costs and quality between different settings. Hatton and Emerson note that research was only just beginning to explore the reasons for such variations. The current policy climate obviously puts emphasis on the development of care standards. The 2003 annual report from the Department of Health noted that plans for care standards would need to be redrawn to make a clearer distinction between supported living and residential care, influencing the work of the National Care Standards Commission.

Felce and Emerson (2004), reflecting on findings from a number of studies, argue that there is strong evidence that quality of life is better for the residents of small group facilities than for those living in larger community accommodation or campus facilities. We return to this and other evaluative evidence in the next section.

A final set of insights on residential accommodation comes from re-analysis of population census data for 1991 by Emerson and Hatton (1998). This analysis points to the wide variations across the UK in the level of provision, although overall provision fell short of previously set government targets. The majority of people with learning disabilities living in residential provision were in 'relatively large-scale congregate care settings'. There were differences in the patterns of service use by ethnic group. 'Young Black men were significantly more likely to be placed in residential provision than their peers from other ethnic groups; young Asian men, young Chinese/Other men and young Asian women were significantly less likely to be placed in residential provision than their peers from other ethnic groups' (p.1).

As well as the differences between parts of the UK revealed by this analysis of population census data, the Learning Disability Advisory Group (2001) set up in Wales pointed out that there is a very different approach to residential accommodation between Wales and England. In 1995, facilities in Wales had on average three residents, whereas in England the average was nearer to 13 in the local authority sector and six in independent sector homes. The report compares findings from Raynes et al (1994) and Perry and Felce (1994) to suggest that facilities in South Wales were smaller and more individually-oriented, allowing more choice and promoting greater community integration. The report from the Welsh group notes, however, that service levels have not expanded in Wales to the extent that most people considered necessary. It is difficult to offer precise figures because official statistical collections do not cover all facility types, leading the report authors to estimate that the current rate of provision in Wales was about 20 places per 100,000 population lower than in England, lower than the norms set in the 1971 White Paper, and lower than the figure discussed for the All Wales Strategy.

Supported living and ordinary housing

There has been growth in the number of people with learning disabilities supported in ordinary housing settings. The influential but contentious King's Fund (1980) report on an 'Ordinary Life' model put great emphasis on the need for ordinary housing arrangements. This was also an emphasis in the All Wales Strategy as long ago as 1983. It is obviously a major plank of the 2001 White Paper proposals for England. The aim is to afford people with learning disabilities the opportunity of a normal life in ordinary community settings.

Figure 8.29 suggests some recent improvements in England in the rates of adults with learning disabilities helped to live at home (per thousand population aged 18-64). This pattern of improvement seems to be a feature across all regions. In terms of overall performance ratings, the proportion of councils deemed worthy of 3* denomination by the Department of Health in England has increased significantly from 62 per cent in 1998/99 to 80 per cent in 2002/03. By this latter year, around 2.6 people with learning disabilities per thousand population aged 18 to 64 in England were living in the community.

Figure 8.30 shows a substantial increase in the unit cost of residential and nursing home care for adults with learning disabilities in England, and particularly in London. The average unit cost in England increased from £471 per week in 1997/98 to £715 per week in 2002/03. Overall, the proportion of 3* rated authorities on this dimension councils has remained stable at around 70 per cent.

In Wales, investment in this service area fell some distance short of the policy aspiration (Felce 2004), an experience shared across other parts of the UK (Braddock et al 2001, Simons 2001). Consequently, few young adults with intellectual disabilities have the choice to leave their family home for a more independent living arrangement. The unpublished paper by Harker (2003) estimates the shortfall in accommodation to meet housing need (as distinct from choice, as the paper notes) to be 25000 places currently in England. If choice is factored into the calculation, the shortfall is likely to be much greater and perhaps as high as 50000. To make serious inroads into the need-based or choice-based shortfall will therefore require a significant turnaround of past achievements.

Felce (2000) reviews the research evidence on housing options, distinguishing between supported living principles and active support notions, the latter developed for people with more severe or profound learning disabilities. We will discuss the evaluative evidence reviewed by Felce in Section 8.7. It is helpful here to summarise the principles enshrined in supported living arrangements: the home should be the person's own, capital facilities should not distinguish supported housing from ordinary housing, individuals should choose where and with whom they live, they should have control over

their living arrangements and how they conduct their lives, arrangements should remain flexible, and relationships with family, friends and community are pivotal. Such aspirations are not always met, as the LDTF (2004) argued: 'Some people with learning disabilities who have been happy where they live feel like their homes are turning into institutions because there are now so many new rules to follow' (p.73). On the other hand, the Task Force also notes that 'many more people with learning disabilities have been able to get their own tenancies with money from Supporting People. Some people with high support needs have been able to take up tenancies' (p.73).

Clearly, however, it is not sufficient simply to provide facilities: commitment is also needed to the kinds of principles summarised by Felce (2000) from the literature. As the 2001 White Paper noted, various studies have shown that housing design alone does not guarantee positive outcomes. The policy intention was consequently to encourage development of a range of housing options so as to offer 'real choice' to people with learning disabilities and their families.

The government's Supporting People programme has achieved a great deal. The 2001 round of SSI inspections found:

Projects initiated under the umbrella of Supporting People were proving to be successful in catering for people with mild to moderate learning disabilities. This good practice needed to be extended to people with more complex needs. Some county councils had a particularly challenging task, with a need to relate to as many as eight separate district councils with responsibilities for housing. Responses from fieldworkers and carers indicated that the relationship between social services and housing has improved in recent years in all councils (Cope, 2003).

The newly established Partnership Boards were asked to have plans for housing services in place by February 2003. About two-thirds managed to achieve this (Department of Health 2003e). There is a particularly close link between these plans for housing development and the plans for closing the remaining long-stay hospitals.

Widening the housing, care and support options available creates the potential for choice, but individuals also need accessible information in order to make choices. Many people with learning disabilities will need advice and support to do this. However, to reiterate a point made earlier, quoting from Felce's (2000) research evidence review:

Achieving the best standards is not simply a matter of putting into place a few pivotal arrangements. There are no levers which mechanistically make a range of other important processes and outcomes fall into place. Small size does not guarantee quality, nor does community location. Ordinary housing design does not guarantee quality and nor does higher or differently qualified staffing. The relationship between outcome and the nature of the

environmental context is mediated by internal organisation, working methods and the procedures which shape what staff do. In other words, quality appears to result from the interaction between a complex array of environmental arrangements, and each of these needs to be determined correctly (Felce 2000 p.45).

Vocational, educational and leisure activities

For decades, services for people with learning disabilities have been heavily reliant on large, often institutional, day centres. These have provided much needed respite for families, but they have made a limited contribution to promoting social inclusion or independence for people with learning disabilities. People with learning disabilities attending them have not had opportunities to develop individual interests or the skills and experience they need in order to move into employment (Secretary of State for Health 2001 p.76).

Although now a few years old, an excellent review of day activity services is provided by Simons and Watson (1999) and this subsection draws heavily on their work. One of the strongest conclusions to draw from their review is of the paucity of good research, perhaps due to lack of consensus as to the aims of day services and about their outcomes, and lack of clarity as to inputs.

We structure this section by looking first at day services and then at initiatives to get people with learning disabilities into employment.

Day services

Figure 8.26 shows the number of clients with learning disabilities in England receiving different types of community-based services in three recent years. Day care is particularly important for those aged 18-64 years. The same is true in Northern Ireland (figure 8.28). Most people attending day care centres were going to the adult training centres and social education centres. Figure 8.27 shows a very significant increase in the number of people with learning disabilities in Northern Ireland receiving home help, which increased from around 500 in 1998/99 to around 750 in 2002/03. A much smaller number of clients received meals on wheels. Wide local variations around these national averages have been reported (Mason 1998), although Simons and Watson (1999) caution that some 'alternative' models of day provision do not get measured in routine statistical collections.

Day care places grew from 38900 to 56700 between 1977 and 1992 (Evandrou and Falkingham 1995). Most of this would have been growth in traditional models of day

services. Indeed, *Facing the Facts*, the review study by the SSI, NHS Executive and DH Social Care Group found that two-thirds of the authorities they examined still relied heavily on adult training centres (many with discredited, often exploitative industrial training models) or social education centres (less often criticised but still usually organised on a large, perhaps institutional scale). Indeed, three authorities planned to increase such use. On the other hand, three-quarters of the authorities anticipated growth in supported employment placements, outreach groups and continuing education. The same message comes through the final report on joint reviews by the SSI and Audit Commission (2004) which noted uneven progress in learning disability services: 'Even in 2003, the traditional day care experience was the horizon for many, with only limited progress made in accessing ordinary community facilities' (p.29).

A few years earlier, Simons and Watson (1999) had suggested that there was collective dissatisfaction with current arrangements, but change has clearly been slow to materialise. Their evidence review uncovered many criticisms of day services from users, including poor food, boredom, bullying and problems with transport. People not using day centres and those who had moved to supported employment were generally more negative about day centres than were current users. Most people in employment schemes were fairly happy but wanted higher wages and/or more hours. Carers appeared to be more resistant to change, valuing day centres for the respite they provide.

The 2001 White Paper had calculated that 80 per cent of local authority spending on day services went to the 60000 or more day centre places that 'often focus on large, group activities' (see Jones and Wright 1996). People with the greatest disabilities often received the worst service. There are also concerns about the people who do not have access to day care (Felce et al 1998). Progress to modernise day services had been slow. The barriers to progress were identified as: difficulties in releasing or redirecting capital and staff resources, slow development of wider community links, limited development of supported employment options, the need to balance respite for families with opportunities for service users, and slow progress with the introduction of person-centred planning. The White Paper therefore announced a five-year programme to modernise day services by urging greater emphasis on individualised and flexible services:

- support people in developing their capacity to do what they want;
- help people develop social skills and the capacity to form friendships and relationships with a wider range of people;
- enable people to develop skills and enhance their employability; and
- help communities welcome people with learning disabilities.

Closer, stronger links with supported employment programmes were included in these plans. Other dimensions of the 'fulfilling lives' agenda for change in the White Paper were:

- education and lifelong learning: recognising needs, opening up access, extending individual rights;
- transport: removing obstacles to using public and private transport ('Sometimes transport was inadequate, often involving the service user in long journeys to and from the centre, work or college placement' Cope, 2003 p.5);
- leisure and relationships: building leisure into individual and community care plans, widening opportunities, promoting inclusion, supporting personal and intimate relationships;
- parents with a learning disability: tackling the often huge social and economic disadvantages they face, providing appropriate support;
- social security benefits: ensuring consistency in decisions on entitlement, overcoming 'benefit trap' disincentives to work; and
- moving into employment as an important route to social inclusion: the 'overall aim is to increase the number of people with learning disabilities in employment and to work towards their achieving parity with other disabled people in the workforce' (p.85). A number of initiatives are set out.

The *Valuing People* Support Team subsequently prepared a toolkit for the modernisation of day services, sent to Partnership Boards in late 2002. However, not everyone is wedded to this new model.

Modernised small-scale residential and day services were available in all councils. Nevertheless, some carers were reluctant to see the large day centres replaced by a range of dispersed local community services. Often carers were only convinced that a dispersed day service was a good option when they had direct experience of it. Only a minority of councils, however, were able to run both services in parallel until confidence was established in the new (Cope 2003 p.5).

In Wales there has been encouragement of a variety of day services for some time, particularly within the All Wales Strategy (Learning Disability Advisory Group 2001). However, 23 per cent fewer people attended day centres in 1995 than in 1988, according to this review, and it may be that charging policies for attendance and transport may act as a disincentive (Simons and Watson 1999). Growth came in attendance at 'non-traditional' services such as 'satellite units, colleges of further

education, work experience, paid employment and a range of other services and community placement options. A few adult training centres or social education centres have been completely re-provided and the old centres closed'. Simons and Watson (1999) note that, while these alternatives were developed, traditional services appear relatively untouched. Resistance to the closure of day centres came from carers. There was also inevitable concern about resources and the high staff costs of more individualised services.

The Learning Disability Advisory Group (2001) described a phenomenon experienced in both Wales and England – the trend towards sessional attendance – making it difficult to compare utilisation levels over time. However, the group conclude that there appears not to have been any overall increase in day services since the start of the All Wales Strategy.

Development of day services for adults under the All Wales Strategy has been, therefore, somewhat similar to the development of residential accommodation in that reform of large centralised provision has taken precedence over expansion of service availability in line with demographic change and progress towards more comprehensive provision. However, reform of the nature of day services achieved to date, although significant, is not as complete as that brought about in relation to residential services. Further reform is anticipated (Learning Disability Advisory Group 2001 section 3).

Employment services

In their evidence review, Simons and Watson (1999) described a number of models of employment support and placement. Sheltered work settings were declining in numbers but were not necessarily unpopular with users. Another model, rarely followed, was the 'social enterprise' approach that paid wages that reflect the worth of the work. As in the mental health field, there has been growing attention paid to supported employment approaches, for which there is some (mainly US) supportive evidence (see section 8.7). The core principle is 'place and train': finding a work placement and supporting people as they adjust and adapt (Beyer 1995). Development at the time of Simons and Watson's review was patchy, with clusters of schemes in the North West, South East, London and Wales. Most relied on funding from social services (58 per cent of total) and health authorities (15 per cent), much of it pilot or short-term funding (Beyer et al 1996). There were barriers to further development of this approach: social services departments did not prioritise employment services, and service users found themselves in a benefit trap. There was a gender bias in supported employment (66 per cent of supported workers were male).

Other models of employment support included vocational training (usually for a fixed period), training and employment (often horticultural or food production), community

businesses (social firms which are more common in Europe but in England have developed more for people with mental health problems), and supported volunteering (these 'social enterprises' are similar to social firms but where not all employees have a full contract of employment). The last two are rare and evidence on them even rarer. The 'Without Walls' services are mostly aimed at increasing inclusion within the wider community, and involve some day activities and employment training.

The government's objective, as set out in *Valuing People*, is 'to enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work' (Secretary of State for Health 2001 p.84). The first annual report from the Department of Health (2003e) noted some progress: the number of people in paid employment was increasing but remained very small. A number of initiatives have been taken to help people get paid work. Ten per cent of people with learning disabilities known to local authorities had jobs in 2000/01, increasing slightly to 11 per cent in 2001/02 and 2002/03. Emphasis continues to be put on employment today. However, the Learning Disability Task Force (2004) expresses concern about wasted money on training:

A lot of money is being spent on training that gets people with learning disabilities ready for work. Many people with learning disabilities have been 'getting ready for work' for a very long time. It would be better to spend this money on getting people into work and supporting them to learn on the job (p.50).

The SSI found a variety of supported employment schemes, 'varying from sheltered workshops to outreach schemes where people were supported in real jobs with good cross-section of employers. Some councils were setting an example by employing people with learning disabilities' (Cope 2003 p.5).

In Wales, there is similarly greater emphasis today on 'supporting people in productive employment rather than programmes of diversional activity' (Learning Disability Advisory Group 2001, Section 3). Indeed, there has been a more rapid growth of supported employment arrangements than elsewhere in the UK (Beyer et al 1996). This advisory group also noted the growing needs for day activities by those people with learning disabilities who are of retirement age.

Targeting

At many points in this chapter we have noted the poor targeting of services on needs, and we do not intend to repeat the detailed evidence here. There are a number of concerns. One is the poor level of support for people with learning disabilities from minority ethnic groups:

Many people from minority ethnic communities are poor, face racism, and face discrimination in employment, education, health and social services. ... Many services do not have the skills needed to work with people with learning disabilities from minority ethnic communities. There is not enough money being put in (Cope 2003 p.20).

The Department of Health's 2003 annual report also registered the government's commitment to better identification of the needs of people from BME communities, and to ensure that services are made available to them in culturally sensitive ways.

One study in this area, by McGrowther et al (2002), collected information for over 2500 South Asian and white adults on the Leicester Learning Disabilities Register. Service utilisation rates were generally similar across the two groups, with the exception of psychiatric services and respite care, both of which were used less often by the South Asian group. However, South Asian carers felt more unmet need for services than whites, particularly for social (rather than health) care, specifically day care, home helps, sitting services. Earlier work on the same case register had also reported a great many unmet needs (McGrowther et al 1996). Unmet needs for those people in residential care included day care (32 per cent of the sample), transportation (16 per cent), physiotherapy (16 per cent) and speech therapy (23 per cent). For those living at home wider range of unmet service needs was reported, including financial help (37 per cent), long-term social support (20 per cent), respite care (27 per cent), speech therapy (20 per cent) and housing adaptation (23 per cent).

Another major concern, discussed most recently by the Learning Disability Task Force (2004), is the poor targeting of services on people with high support needs, defined as people with a profound learning disability, challenging behaviour, sensory impairment, physical disability, autism, mental illness, or having committed offences. Those from minority ethnic communities with high support needs are doubly disadvantaged. People with high support needs are often denied choices, rights and independence. Families supporting people with high support needs are themselves not getting enough support from local agencies. Many of the people who are still to move out of long-stay hospitals are those with high support needs. A particular concern is that locally available services are often not available, meaning that people with high support needs have to move long distances across the country in order to receive the services they need. This same point is made in the SSI summary of inspections (Cope 2003). One of the consequences is that people with high support needs end up in 'special' services that leave them even more socially excluded.

Third, there is poor access to mainstream, general and mental health care: the SSI found 'significant variations in access to specialist health services within and between localities' (Cope, 2003). Other access difficulties relate to the unmet needs of people who also have physical disabilities or sensory impairment.

The *Fair Access to Care* guidance issued 2001 set out eligibility criteria for adult social care services with the intention of improving consistency of access and level of support.

Quality assurance

The 2001 White Paper devoted a lot of space to the need to raise the quality of services:

Quality assurance in learning disability services is currently underdeveloped. Few places have achieved a holistic approach that systematically draws on all sources of information and research, including feedback from users. Complaint procedures are often inaccessible. People from minority ethnic communities are too often at the margins of services and funding, and people with learning disabilities do not always receive adequate protection from abuse and exploitation. The challenge for agencies working in the learning disability field will be to:

- develop a better approach to measuring quality, which emphasises improved outcomes as informed by the best quality research;
- work in partnership with other agencies in developing benchmarks for measuring performance;
- enable people with learning disabilities to lead lives safe from harm and abuse;
- put the needs and wishes of the person using the service at the centre of their quality assurance systems (Secretary of State for Health 2001 pp. 82-83).

The planks on which quality assurance would be built were the regulatory framework introduced by the Care Standards Act 2000 (which requires that every service user has an individual plan), the evidence-based practice to be recommended by SCIE, local quality frameworks and clinical governance, user surveys and complaints procedures, the new Learning Disability Partnership Boards (particularly in relation to minority ethnic communities), the *No Secrets* guidance to protect vulnerable adults from abuse and harm, better support for vulnerable witnesses, and guidance on the use of physical interventions. The White Paper also reiterated the government's commitments to Best Value and whole systems perspectives.

The first annual report by the Department of Health (2003e) includes a chapter on quality of services, again one of the objectives set out in the 2001 White Paper. Guidance was issued on good practice in physical interventions. Revised minimum standards in residential care were issued in February 2003. Another focus was on abuse, supporting carers from minority ethnic communities, supporting people giving evidence in court, a user survey, and a number of other things.

Setting service-related targets

We referred earlier to the concern expressed by Felce (2004) that the English government had retreated from the setting of targets in terms of service provision, on the basis that such targets would be inappropriate until the individual needs of people with learning disabilities have been established.

Targets such as those set in the 1971 White Paper *Better Services* at least provide some means of holding authorities to account and identifying regional inequalities. They express a commitment to provide and fund a certain availability of support. Whilst it may be in the interest of government to avoid stating such commitments, their absence does not serve those dependent on service support. I think I am correct in saying that it is now impossible to locate a single quantifiable provision target in any of the British National Policy Statements. There is a target to close institutions but critically not for the level of alternative provision. As my colleagues and I argued in summarising research on the All Wales Strategy, there is no incompatibility between setting indicative provision targets for populations as a whole and individual assessment of the precise nature of service input different people require or want (Felce et al 1998 p.202-204). I am concerned that we have traded one for the other, and I think we require both (p.29).

The 2001 White Paper, for example, includes many expectations, but few or perhaps no precise targets. Felce points to examples where the absence of strategic targets would potentially generate difficulties, a concern shared by Mansell and Beadle-Brown (2004a). These authors criticise the approach taken in the 2001 White Paper, in that 'major influences on the need for resources could be sidelined in public policy until an indeterminate point in the future. The resulting resource constraints would likely undermine the ability to turn person-centred plans into action' (p.32).

8.7 Outcomes and cost-effectiveness

The dimensions of outcome relevant to a discussion of effectiveness and cost-effectiveness are going to be similar to those discussed in the needs section. Evaluations of policy initiatives and practice models have tended to employ these and a range of other measures. Stancliffe (2004) provides a useful, up to date discussion of

the choice of outcome dimensions in the context of research on residential supports. He also reflects on trends in outcome measurement. Early research focussed on adaptive and challenging behaviour. As normalisation and related ideologies and approaches to practice came to be more widely discussed and implemented so research began to widen its evaluative lens to measure service users' and carers' satisfaction levels, subjective quality of life, economic status (income, employment), community participation, social networks, choice, self-determination, physical and mental health status, rights and access. Multiple outcome measures are needed to capture the complexity of community living.

One quick word is necessary here on the use of measures of service user satisfaction. A number of authors question the validity of such indicators when assessing quality of life for people with learning disabilities (e.g. Hensel 2001) or as proxies for outcomes (Stancliffe 2004). This is a generic issue to which we return in chapter 9.

We structure this section as follows:

- Person-centred planning and care management
- Hospital closures
- Supported accommodation
- Day activities and employment
- Family support
- Other

The evidence base in relation to the range of accommodation options (the third subsection) is quite large, and there are a number of elements within it, but there are relatively few studies in most other service areas. There are also not very many systematic reviews (at least that we could find).

Before looking at the service-related evaluative evidence it is interesting to consider work by Beadle-Brown et al (2000) who studied the communication, self-care, educational and cognitive skills of people with learning disability and how they change over time. They studied a large cohort of people first identified when aged under 15 in December 1970. Beadle-Brown and colleagues found no link between changes along these dimensions and support service use. The greatest changes occurred for those people who were chronologically youngest at the start of the study. In relation to service links, 'the residential situation [that is where the person lived] appeared to be affected by the level of ability of the child, rather than the level of ability being a result of the

residential situation. Those children who were less able mentally and physically were those who were placed in a hospital or specialised home, while those who were more able stayed at home with their parents for longer' (p.23).

Person-centred planning and care management

When discussing the development of individually focused ways of organising services and meeting the needs and preferences of people with learning disabilities in section 8.6 we referred to the thin evidence base on person-centred planning and other 'lifestyle planning' models. This was one of the reasons for the concerned view of the 2001 White Paper proposals cogently argued by Mansell and Beadle-Brown (2004). A systematic review by Rudkin and Rowe (1999) looked for and at studies of lifestyle planning (the generic term used to subsume a range of models, including person-centred planning and case management). No randomised controlled trials were found. Five studies using other designs were included but the service orientation of one of these five is (by our reading) inappropriately included in this review, and the robustness of at least another two of the included studies must be seriously questioned, and we were surprised to see them accepted as offering valid evidence. At least two of the studies were conducted outside the UK. The evidence base offered by Rudkin and Rowe (1999) for what is a major component of learning disability policy in England is therefore so thin as to be translucent.

Two studies completed since Rudkin and Rowe's review offer a little more encouragement. Hassiotis et al (2001) looked at the subsample of people with severe psychotic disorder included in the UK700 trial (which we described in chapter 5) with what they called 'borderline IQ' (that is, mild learning disability). For these people they found that intensive case management was better than standard case management in terms of the number of inpatient hospital days over a two-year period and in total cost. (The authors define the former as their primary outcome measure, but as the largest single component of cost is inpatient admission, the cost-effectiveness argument appears to be circular and surely tautological.) On the secondary outcomes, however, those people supported by intensive case management had fewer needs, fewer unmet needs and greater satisfaction by the two-year follow-up point than those supported by standard case management. They concluded that 'The multi-dimensional and intensive focus of ICM [intensive case management] appears to be suited to the complex needs of patients of low IQ with psychosis ... but this "hidden" group of patients needs more systematic study' (Hassiotis et al 2001 p.170).

Hospital closure

A decade ago, Emerson and Hatton (1994) reviewed the evidence on people with learning disabilities moving out from hospital to community residence. On most dimensions the community-based arrangements were superior to hospital. These authors subsequently reviewed a range of residential settings, including hospital, and we shall summarise their conclusions in the next subsection ('Supported accommodation'). Since Emerson and Hatton completed their review other studies of relevance to this chapter have been completed and we shall also briefly summarise those other findings in the next subsection.

Before we do so, we should summarise another review. The Learning Disability Advisory Group (2001) summarised experience in Wales and elsewhere. The conclusion was that supported community housing compared favourably with hospital accommodation with respect to the material environment, the resident-oriented milieu, staff attention to residents, access to community activities, opportunity for the use of skills, choice, the amount of constructive activity, and resident satisfaction with life. Felce and Emerson (2004) note that studies have found greater levels of engagement in activity in community settings compared to hospitals.

Supported accommodation

The greatest volume of evidence is available from studies of different community-based accommodation settings. In fact, these studies are not simply comparing the effectiveness or cost-effectiveness of accommodation but all of the associated services, lifestyle arrangements and opportunities that tend to accompany accommodation types. There is one particular difficulty in reviewing the evidence, however, relating to the labelling and classification of settings.

Descriptions of different forms of residential supports are notoriously imprecise. ... The terminology associated with community-based residential supports ... [reflects] national systems of administrative classification (such as 'residential care home' in the UK; 'intermediate care facility – mentally retarded [ICF-MR]' in the USA) and poorly defined 'models' of support (such as 'supported living' and 'group homes') that often contain elements relating to both the structural characteristics of settings (such as the number of cohabitants), tenancy arrangements (such as residence owned or leased by consumers), and internal processes for delivering support (such as emphasis on self-determination in supported living) (Stancliffe 2004 p.460).

In fact, three evidence reviews help us to cut through the imprecision and to summarise the accumulated evidence. Each is now a little out of date and we will need to refer to more recent evidence after summarising what these reviews concluded.

The earliest of the reviews, and a good starting point is the work of Emerson and Hatton (1994), looking first at hospital resettlement processes and their consequences, and subsequently carrying out a wider-ranging examination of all of the relevant literature on residential settings (Hatton and Emerson 1996). Although the timing of their reviews means that they have covered only the start of the period that concerns us in this report, what they found and the concluded is enormously useful. They thoroughly examined the UK and Irish evidence and focused their summary of findings on differences in outcomes, care processes and costs between mental handicap hospitals, hostels, group homes and independent living schemes. They organised their findings under 14 heads representing the most relevant outcome, process and cost dimensions. In a moment we will employ their structure. For each dimension we will first quote the summary of the findings offered by Hatton and Emerson (in bullet points under each subheading), and then add any other evidence from other reviews and studies.

Chronologically, the third of the reviews was carried out by Felce (2000) and it makes sense to summarise his findings under the headings suggested by Hatton and Emerson.

However, the second review needs separate treatment. Dagnan (1997) concentrated on family placement schemes, defined as accommodating four or fewer people in one household, as part of an organised scheme (usually with social services department involvement) that seeks to match the needs of people with learning disabilities and carers, that are continually monitored, and that offer 'the opportunity to become part of the carer's existing family or social network' (p.594). In the UK and elsewhere, similar arrangements have been called family care, family foster care, small family homes and home care. British and American models differ in certain respects, as Dagnan describes, including the less extensive use of this model of care in the UK and the tendency for fewer people to be placed in each home in the UK. We extract from the report of the review only those findings relating to the outcomes and processes relevant to this chapter and coming from UK studies. (There are no findings relating to cost-effectiveness in Dagnan's review and it is not known from the paper whether this element was excluded or whether there was simply no evidence. We suspect it is the latter.)

There is evidence that people in family placement schemes used a variety of unsegregated leisure and other community facilities, and in ways similar to people living with their natural families. However, roles adopted in families may not always have been age-appropriate. In some placements people with learning disabilities appeared to play unnecessarily restrictive roles, but many carers were trying to improve skills. There is a

little evidence on carer stress from British studies, particularly when service users have greater physical needs and challenging behaviour, but it appears to be anecdotal. Carer motivations for entering family placement schemes combine financial reward with a wish to provide care (previously met in a professional or parental role), a need for company and 'fulfilling personal convictions about appropriate care' (Dagnan 1997 p.599).

Since these three reviews were completed a few other studies have added to our understanding of the effectiveness and (less often) the cost-effectiveness of different accommodation arrangements outside hospital. The most significant of them was the DH-funded study of village (or intentional) communities, NHS campuses and community-based residential services (including supported living arrangements). This study was able to collect data for quite a large number of people across a range of settings. The results cover many dimensions and are reported in a range of papers, including Emerson et al (2000, 2000a, 2001b), Gregory et al (2001), Hallam et al (2002), Robertson et al (2000, 2000a, 2001, 2001a) and Walsh et al (2001). To avoid endless repetition of citations we shall refer to this as the *community residential supports study*. The evaluation, carried out between 1996 and 1998, collected data relating to independent sector village or residential communities, NHS residential campuses built, or converted to accommodate former long-stay hospital patients and small community-based dispersed housing units (group homes and supported living arrangements).

Social indicators

- Group homes provide a more pleasant and less institutional physical environment than either hostels or hospitals, although there was wide variation in the quality of physical environment in group homes.
- People living in group homes or hostels have more personal possessions than people living in hospital.
- Rates of employment across all settings were uniformly low.

Dispersed community housing was generally rated as being more homely and less restrictive than village communities or NHS campuses (Emerson et al 2000). Community re-provision improves service users' living environments in the short term (Knapp et al 1992, Cambridge et al 1994) and maintains it in the much longer term (Carpenter et al 2004). Independent sector and smaller community facilities may be more home-like (see evidence collated by Felce 2000, p.20).

Medication

- People in hospital are more likely to be prescribed psychoactive medication than people in community-based settings, although levels of prescription in all settings were high.

Felce (2000) questions this conclusion, arguing that earlier research did not adequately standardise for resident characteristics. He could not find evidence of lower psychotropic medication use in community settings compared to institutions. He also notes that health status and mortality have rarely been researched in learning disability evaluations.

User satisfaction

- People living in community-based settings (and in particular those living in group homes) report greater satisfaction with their place of residence and life in general than people living in hospital.
- The majority of people living in hospital express a preference to live in more independent settings, while the majority of people living in community-based settings express a preference for staying where they are.

Satisfaction levels tend to be higher when they have more independence, are actively supported in activities, greater privacy, having more friends with learning disabilities, being more active in the community (Felce 2000, Emerson et al 2000). Within the dispersed housing group there were no differences between supported living schemes, small or large group homes.

Choice

- People living in community-based settings (and in particular those living in group homes) have greater privacy and choice over everyday aspects of their lives, although the differences are often marginal. However, people across all settings appear to have little influence over major life decisions.

The community residential supports study found that village communities and NHS campuses offered fewer choices to residents than dispersed housing arrangement. Supported living schemes offered greater choice when compared to small group homes (Emerson et al 2000a, 2001). Autonomy may be associated with lower staff-to-resident ratios (Felce et al 1999).

Competence and personal growth: adaptive behaviour

- People moving from hospital to community-based settings may show some modest gains in adaptive behaviour [skills] which are likely to be maintained (but not built upon) over time.

The twelve-year follow-up study of people leaving long-stay hospital found that skills improved immediately after resettlement (Knapp et al 1992), were maintained at five years (Cambridge et al 1994) but had declined marginally at twelve years (Carpenter et al 2004). Mansell et al (2003) argue that more attention should be given to efforts within small community homes to improve resident engagement, given the limited scope for improving adaptive behaviour. In an earlier paper it was shown that homes adopting 'active support' approaches could improve both engagement and adaptive behaviour over a three-year period (Mansell et al 2002).

Competence and personal growth: challenging behaviour

- Overall, no changes in the rated severity of challenging behaviour are apparent on moving from hospital to community-based services. There is a trend, however, for observed levels of challenging behaviour to decrease on the move from hospital to community-based settings.

This last conclusion was not borne out in the twelve-year follow-up study (Carpenter et al 2004) but measurement may not have been sensitive and there were few people with challenging behaviour in the sample. Felce et al (1998) looked specifically at people with severe challenging behaviour and found a significant improvement in community housing settings but not in hospital.

Participation: domestic and other activities

- Rated and observed levels of the participation of users in domestic activities are higher in community-based services (and in particular in group homes) than in NHS mental handicap hospitals. There is, however, marked variation in the extent to which users participate in everyday activities.

In the community residential supports study, supported living residents had fewer hours of scheduled activity than residents in small group homes (Emerson et al 2000a).

Participation: friends and families

- There are few, if any, differences in levels of friendships or contact with families between service models. Where differences have been reported, they suggest greater levels of friendships and contact with families in community-based settings. Levels of contact with friends appear uniformly low across all types of services.

Residents of small group homes had larger social networks than residents of large group homes and more people in their networks who did not have learning disabilities or were not staff (Emerson et al 2000a, 2001).

Community presence

- People living in community-based services (and in particular in group homes) make more use of ordinary facilities in the community than people living in hospital.

Felce et al (1998) and Emerson et al (2000) offer later confirmatory evidence. Community participation is greater for people in dispersed housing compared to village communities or NHS campuses, and frequency and variety increase over time. Dispersed housing tends to be better located in relation to community amenities (Felce 2000).

Status and acceptance

- Neighbours and local business people report few concerns about living next to or serving people with learning disabilities. People with learning disabilities living independently, particularly in poor areas with 'hard to let' tenancies, may report victimisation.

The community residential supports study found lower rates of abuse and victimisation in village communities than in dispersed housing or NHS campuses. However, vandalism of the home and exploitation in the local community were more likely in supported living environments than in small group homes.

The views of parents and relatives

- Parents express greater satisfaction with community-based services than with hospitals. Only a small minority of parents express overall negative views about the support their son or daughter is receiving in community-based services, although specific concerns were noted by a larger proportion of parents.

Service practices

- Community-based services (and in particular group homes) are more resident-oriented and less institutional than hospitals. There is, however, wide variation in the practices of community-based services.
- People living in community-based settings make greater use of 'ordinary' health services than people in hospital.

The community residential supports study found that people in NHS campuses and village communities had higher rates of routine health checks than people in dispersed community housing, although there were no differences in being under-or over-weight, smoking, alcohol consumption or adequacy of diet (Emerson et al 2000). Health-related activity rates were better in dispersed housing and village communities than in NHS campuses. The SSI inspections in 2001 concluded that people 'living in ordinary houses in the community ... were increasingly using mainstream health services. At best, they could access a range of specialist health services, such as occupational therapy, speech therapy, clinical psychology and psychiatry. At worst, one or more of these services were unavailable, generally because of difficulties in recruitment to key posts' (Cope 2003 p.4).

Staff contact

- People living in community-based services (and in particular those living in group homes) can expect to receive more contact from care staff than people living in hospital. There is, however, marked variation in the levels of contact received by people in all settings.

Stancliffe (2004) notes the limited research base on measures of basic resources such as staffing and resident outcomes.

Costs

- Studies which have examined the comprehensive costs of residential services have all reported marked variation in costs within models. There are no clear differences between the comprehensive costs of community-based services and mental handicap hospitals.

A number of studies have estimated and compared the costs of hospital and community-based accommodation for people who were resettled in the community. For example, Korman and Glennerster (1990) found costs were greater for NHS-managed community facilities than for hospital placements. A large-sample evaluation of hospital discharges in Northern Ireland found that community provision was less expensive than hospital care, with statutory sector facilities being the most costly arrangements outside hospital, and private residential and nursing homes the least costly (Beecham et al 1997). In another Northern Ireland study, Hughes et al (2003) estimated the costs to a hospital of the process of community resettlement. Dockrell et al (1995) compare hospital and community costs for a small sample of people with mild learning disabilities, but there seems no possibility of generalising from their findings.

The five- and twelve-year follow-up studies of people resettled by projects in the Care in the Community demonstration programme initiated by the Department of Health in the mid 1980s offer encouraging results. As part of this multiple-client group programme, almost 400 people with learning disabilities moved to a variety of community residences through twelve separate local schemes in England. We presented some cost evidence at the twelve-year point in section 8.4. Over the full period, the research found that the costs of the full support arrangements in the community were significantly higher at the one-year follow-up than in hospital (Knapp et al 1992), had fallen slightly by five years (Cambridge et al 1994), but were then effectively no different from the (inflation-adjusted) costs at twelve years (Hallam et al 2004). No evidence was found at either five or twelve years of any significant association between the costs of support and changes in either skills or behavioural problems between the hospital and community assessments (Cambridge et al 1994, Hallam et al 2004).

In the community residential supports study, dispersed housing schemes were significantly more expensive than NHS residential campuses which were, in turn, significantly more expensive than provision in voluntary sector 'village communities' (Emerson et al 2000, Hallam et al 2002). Looking within the sample, higher costs were found to be associated with lower levels of ability and with younger users, for whom more costly residential supports and more innovative day programmes were provided (Emerson et al 2000). Unlike the findings of Shiell et al (1993) there were links between higher cost and smaller facilities and, in addition, several indicators of the quality of care impacted on cost. Generally, more sophisticated procedures (for example, activity planning for residents and individual personal plans) were associated with higher cost. Where less sophisticated procedures existed for staff training and supervision, however, the cost was also higher. This may be because ill-defined internal procedures for training and support of staff result in higher staff turnover, lower morale and higher levels of staff sickness.

Day activities and employment

A wide-ranging review of the provision and consequences of day activity services, including employment 'programmes', was published five years ago (Simons and Watson 1999). There is a striking lack of evidence on many aspects of day services and supported employment. This dearth is compounded by an absence of consensus about the function of day services, and about their outcomes and how to measure them. For example, the respite function of day care for family carers is rarely recognised and the needs of carers are rarely taken into account when designing services. Although new ('alternative') forms of day provision have been introduced, as we discussed in section 8.5 the traditional day centre continues to dominate in terms of the scale of provision.

Simons and Watson (1999) review the evidence on outcomes under five headings: engagement in meaningful activities; time spent in non-segregated settings; the development of wider relationships; impact on income; and user and carer views.

The level of ability appears to predict engagement in meaningful activities

(Pettifer and Mansell, 1993), but levels vary enormously: people with higher support needs tend to disengage, spending only 12 per cent (66 minutes in a five-hour day) in constructive activity compared to 66 per cent for the most able users. Levels of engagement increase with intensity of support (Allen and Lowe 1995; Reid et al 1998). Levels of engagement have also been found to be higher in supported employment services than in day centres (Kilsby and Beyer 1996).

Only 11 per cent of day centre users spent all their time in the segregated setting of a day centre (Beyer et al 1994). As Simons and Watson (1999) note, 'day centres have become more outward looking in recent years' (p.43). However, the SSI (1995) reported that non-centre based activities do not necessarily mean more integration. Often, for example, leisure facilities were used as a segregated session. Even the workplace need not represent an integrated setting.

The third outcome dimension considered by Simons and Watson was the development of wider relationships, beyond the 'limited world of learning disability services' (p.44). Success in this regard is quite limited. For example, Pilkington (1991) reports modest achievements by the Stockport Leisure Link scheme. Relationships will not necessarily flow from a physical presence in non-segregated settings. Studies are beginning to suggest supported employment schemes might be bucking this trend, though all of the studies are small. Training housing and support service staff in the 'active support'

model may help people with learning disabilities to build relationships in the wider community (Felce 1996).

Another important effectiveness dimension must be income, partly because many day activities have a work focus and because poverty is endemic among people with learning disabilities and (very often) also their families. Research suggests that rates of pay have improved since 1991, with 63 per cent of workers in one study earning over £3 an hour in 1995 (Beyer et al 1996). Charges for services and transport can have a real impact on their low incomes, as can benefit complications. Most people nevertheless gained (albeit modestly) from working.

There have been few large-scale studies of day services that have obtained user views. LeTouze and Pahl (1990) found that views were generally positive (as did Jahoda et al 1989), but that about half the users wanted something different. 'While day centres are liked by many users, they also have their critics and are the subject of a wide range of complaints' (Simons and Watson 1999 p.6).

Supported employment initiatives took off more rapidly in Wales than elsewhere in the UK (Learning Disability Advisory Group 2001) and two evaluations of South Wales schemes offer helpful evidence. One included what the authors called a cost-benefit analysis (Beyer and Kilsby 1998) and the other examined the cost-effectiveness of supported employment arrangements (Shearn et al 2000). The Beyer and Kilsby study of two agencies was effectively a before-after comparison without a control group of people not in supported employment schemes. It looked at the full costs of the programmes and – on the 'financial benefit' side – the income earned, tax and national insurance paid, reductions in welfare benefits and reduced use of other day services. There were no measures of outcomes for service users (other than income) and no incremental analysis, which make it hard to know what broader conclusions to draw from this study. Nevertheless, the study is enormously useful in calculating, with some care, the expenditure on and cost-offset implications of supported employment and the income earned by service users. Beyer and Kilsby's conclusion that the costs of running the programmes exceeded the financial benefits for the taxpayer and for society more generally, must be weighed against the (modest) financial gains for people placed in employment and possibly (although unmeasured) the non-monetary (quality of life) advantages.

The second study looked at the cost-effectiveness of supported employment for people with severe learning disabilities and high support needs (Shearn et al 2000). Comparisons were made between people who had been found employment from a special needs unit (SNU) of a traditional day centre and people who received the SNU service only. For those in employment a comparison was also made with the situation when they attended the SNU. The cost-effectiveness ratios are not measured incrementally, and the sample size is very small (seven people placed in work, one of

them unpaid), so it would be unwise to make too much of the findings from this study. The authors themselves are cautious about the conclusions to be drawn, but employment conferred some advantages but at a higher cost than the SNU.

Family support

In section 8.4 we discussed the roles of carers, and in 8.5 the family support services being offered. There is some evidence of impact (see those earlier sections, and see Learning Disability Advisory Group 2001 Section 3), but the evidence does not appear plentiful.

Other

We have found very little evidence on the effectiveness or cost-effectiveness of preventive services or strategies. Gilbert et al (2001) evaluate different approaches to screening, examining reductions in the number of liveborn babies with Down's syndrome and the costs of achieving such an outcome.

There also appears to be little systematic evidence on the effectiveness or cost-effectiveness of mental health treatments for people with learning disabilities (Emerson et al 2001 pp.38-39). In the Cochrane library we could only find two systematic reviews relating to people with learning disabilities. One related to the use of antipsychotic medication for people with schizophrenia and learning disability, finding only one randomised controlled trial which had usable evidence for only two people (Duggan and Brylewski 2004, last updated April 2001). No conclusions are possible. The other Cochrane review looked at interventions for people with learning disabilities who are described as sex offenders, which found no randomised controlled trial (Ashman and Duggan 2004). We do not know if studies have been carried out using other designs, and unfortunately these reviews are designed in a way that cannot tell us. We might expect a programme such as the Cochrane Collaboration devoted to the synthesis of medical research to cover the major service areas in the learning disabilities field, but it was nevertheless a little surprising that the health needs of people with learning disabilities have not been *separately* reviewed, even given the modern day policy emphasis on 'mainstreaming'.

When we searched the Campbell Collaboration website we could not find a single review of learning disability services or interventions.

8.8 Choice

The 2001 White Paper offered an array of proposals that were intended to

- ‘tackle social exclusion and achieve better life chances;
- ensure value for money from the large public investment in learning disability services;
- reduce variation and promote consistency and equity of services across the country;
- promote effective partnership working at all levels to ensure a really person-centred approach to delivering quality services;
- drive up standards by encouraging an evidence-based approach to service provision and practice’ (Secretary of State for Health 2001 p.22).

Underpinning these proposals was the core objective of promoting independence, choice and control.

Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. But for too many people with learning disabilities these are currently unattainable goals. We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day-to-day lives (Department of Health 2001 p.24).

What this might mean in terms of the expectations of service users with more complex needs was interpreted in the SSI summary report:

People with learning disabilities with more complex needs should be offered choice and control over their lives, and efforts should be made to discover their wants and needs by using more accessible forms of communication. Advocacy arrangements should allow service users and carers to participate more meaningfully in planning and review meetings. More robust strategies for developing advocacy should be developed (Cope 2003 p.18).

Although choice is at the heart of health and social care policy discussions today we have to remember that it was central to the 1989 White Paper: ‘Promoting choice and independence underlies all the government’s proposals’. However, as a number of commentators have pointed out, the underlying motives at that time were a complex

interweaving of market-like choice concepts with the promotion of individual self-determination (Stalker and Harris 1998).

Choices are constrained in a number of ways, including: the failure to recognise the rights of individuals with learning disabilities as ordinary citizens; the patchy provision of advocacy services; the very limited involvement in decision making; the low take-up of direct payments; the exclusion of people with learning disabilities and their families from many planning processes; poor efforts to communicate with people with learning disabilities in ways that allow them to participate appropriately in decision making; and not acting on the expressed preferences of those people who *do* participate. Three recent studies illustrate these participation failings. A SCIE report questioned whether involving people in service planning and development – admittedly not the same as choice – actually made any difference (Carr 2004). Service users' views may be voiced, may even be heard, but are not necessarily acted upon. Cambridge and McCarthy (2001) expressed doubts about employing user focus groups in *Best Value* and related reviews. And work undertaken by a team of people with learning disabilities to develop a training pack similarly documented how service users were excluded from meetings and not involved in relevant decisions about organisations and projects (Baines et al 2001).

A number of proposals were set out in *Valuing People* to address these deficiencies, including the establishment of a group to advise the Disability Rights Commission. Another initiative is to fund (modestly) further advocacy services, to develop both self-advocacy and citizen advocacy. The aim is to offer a choice of independent advocacy services in each area.

The Department of Health's first annual report (2003e) noted some progress in this last respect, with the establishment of more local advocacy groups, stimulated by some financial support from central government, although this was not enough to satisfy the Learning Disability Task Force (2004). In 2002/03 local authorities were reported to have spent about a third more on advocacy than in the previous year, although there was wide variation across the country. In chapter 8 of the report, the Department of Health discussed developments in the extension of greater choice and control to people with learning disabilities and their families, particularly over where and how they live. Guidance was issued on housing, care and support options, although not as quickly as hoped because of the need for local consultation with Partnership Boards. A great deal of reliance was clearly placed on Supporting People funding for independent living arrangements. The report also agreed with the *Valuing People* Task Force that

people across government as a whole are not taking *Valuing People* seriously enough when they make new plans and changes to ways of doing things; Partnership Boards have had to do a lot of things very quickly. This has made it hard to work well with people with learning disabilities (Department of Health 2003e p.16).

In the following year's annual report, the Department of Health (2004b) reiterated the government's commitment to self-advocacy and citizen advocacy, and continued to provide a small fund to assist. The Mental Incapacity Bill (to be renamed, following lobbying, the Mental Capacity Bill when it is published later in 2004) addresses related issues concerning decision making. One concern expressed by the LDTF (2004) was that 'the new draft Mental Incapacity Bill could be used to stop people with learning disabilities from making their own decisions' (p.39). Other initiatives pertinent to choice and control include rewording of the Sexual Offences Act (to take force from May 2004) 'to reflect the right of people with learning disabilities to a full sexual life' (Department of Health 2004b p.23) and facilitation of the use of Consumer Direct, the helpline set up by the Department of Trade and Industry.

The 2004 report describes initiatives taken to promote choice over where and how people with learning disabilities live, giving most prominence to housing schemes funded by Supporting People. Over £400 million of Supporting People money was spent in 2002/03 on people with learning disabilities, and it was expected that a similar amount would be spent the following year.

As we have noted in previous chapters, for service users to have genuine choice and control at least things must hold: there must be sufficient diversity so as to offer more than one option; there must be sufficient information on those options that is accessible to service users (and their carers); and service users (and carers) must have the power to use that information to control their lives. A fully supported, person-centred, unrestricted direct payments system offers arguably maximum choice and control.

Using this simple framework we can see that, for people with learning disabilities, there seems to be some agreement about what is needed to improve choice and control. Obviously there needs to be greater investment in many localities so as to broaden the range of accommodation, day and other services. We have already discussed how, for example, the range of day activities has been widened away from the traditional and sometimes quite institutional adult training and social education centres (although they are not unpopular with users, and the rate of change has been quite modest), with more emphasis today on supported employment arrangements. Accommodation options are also growing, but very unevenly:

Choice of services varied greatly. Most councils were well on the way to modernisation, and offered a wide range of community-based flexible options, but some provided relatively inflexible accommodation, day care and short-term break options. Surprisingly, there were some councils which did not have any form of adult placement scheme – either for respite or long-term care. This was a serious omission as such schemes were well liked by carers and offered a cost-effective solution to the challenge of re-providing services (Cope 2003 p.23).

However, diversity alone is insufficient:

For choice and control to be meaningful, service users and carers have to have clear information. Some councils provided information in a range of formats, including the internet, and supported this by advocates and specialist disability information services. ... However, most people still use the telephone or visit an office to gain information. Best practice would suggest that information should be available in the format preferred by service users and carers. Unfortunately this was still not the norm. In some councils information was available in day centres but not area or district offices (Cope 2003 p.3 and p.18).

In other words, well-communicated information and support through advocacy must accompany any programme of service development. We have already noted the commitment to expand advocacy. On communication, the 2001 White Paper made a commitment to expanding access to specialist communication equipment:

Assistive technology can increase their [people with learning disabilities'] control, choice and independence through improving cognitive and social function. It can also enable people with learning disabilities to make good use of education, training and employment opportunities (p.52).

The SSI inspections in 2001 found practice to be best in areas with a specialist team to train staff and carers in communication skills (Cope 2003).

Hatton (2004) discusses the definition of choice and the tendency (wrongly, he argues) to see it as synonymous with, rather than one (key) element of control and self-determination. He goes on to discuss the capacity of people with learning disabilities to make choices, which constitutes a 'substantial strand of research'. This obviously raises the issue of conflicts of interest between people with learning disabilities and their family carers, many of which arise because of an inadequate service system that provides insufficient support to the individual (Williams and Robertson 2001). These authors recommend that 'a greater degree of informed choice for individuals with intellectual disabilities will in itself resolve many potential conflicts of interest' (p.30).

Hatton reviews studies that have assessed the extent to which people have opportunities to make choices. An earlier review by Harris (2000) looked at the meanings attached to the concepts of choice and empowerment in the learning disability literature, and Stalker and Harris (1998) reviewed the exercise of choice. The latter is especially helpful although now a little out of date. There is also a sizeable literature on the evaluation of interventions to improve choice-making skills, for example

improving choice-making behaviour in everyday settings and improving skills as a component of self-determination: Hatton (2004) refers to a systematic review by Algozzine et al (2001). In Section 8.6 we summarised evidence on the different opportunities for, and achievement of choice by people living in different types of residence. Community-based settings are clearly superior to hospital in this regard, although there is great variation across community settings. Smaller, newer facilities generally perform better than larger facilities. The domains over which choice can be exercised also show some variation between settings, and people with mild or moderate learning disabilities have more opportunities to exercise choice than people with more severe disabilities or with challenging behaviour (Stalker and Harris 2000 and the references therein).

Choice should be seen not so much as an end in itself but as a means to improve lifestyle. Hatton (2004) refers to the systematic review by Kern et al (1998) which looked at choice-making as an intervention to improve behaviour. He notes that 'behavioural interventions have demonstrated that improving choice can have a socially significant impact on the lives of people with severe or profound intellectual disabilities. Perhaps the next challenge is to demonstrate the applicability of such interventions to routine practice; can such interventions be effectively used for larger numbers of people, in a wider range of settings, with staff groups in routine service settings?'

The White Paper Valuing People notes that 'Many people with learning disabilities have little choice or control in their lives. Recent research shows only 6 per cent of people with learning disabilities having control over who they lived with, and 1 per cent over choice of carer. Advocacy services are patchy and inconsistent. Direct payments have been slow to take off for people with learning disabilities' (p.19).

To conclude, therefore, involving people with learning disabilities in the decision-making process – exercising choice and control – is a key aim of current government policy:

This applies to decisions on day-to-day matters such as choice of activities, operational matters such as staff selection and strategic matters such as changes to eligibility criteria. It is no longer acceptable for organisations to view people with learning disabilities as passive recipients of services; they must instead be seen as active partners (Secretary of State for Health 2001 p.51).

Table 8.1 the estimated prevalence of intellectual disability in Britain

Age group	Number of people resident in households	Number of people in communal establishments	Total number of people	1986 population (000s)	Prevalence rate (per 1000)	95 per cent confidence interval
0-4	5686	195	5881	3506	1.7	0.9-2.4
5-9	6844	696	7540	3337	2.3	1.4-3.1
10-15	17905	196	18101	4407	4.1	3.1-5.1
16-19	21519	608	22127	3486	6.3	4.7-7.9
20-24	16644	7094	23738	4648	5.1	3.5-6.7
25-34	28732	12465	41197	7807	5.3	3.9-6.6
35-44	18590	10540	29130	7530	3.9	2.8-5.0
45-54	8578	6587	15165	6012	2.5	1.7-3.3
55-64	3590	8817	12407	5969	2.1	1.1-3.1
65-74	5648	7702	13350	4892	2.7	1.5-4.0
75+	2295	5979	8274	3602	2.3	1.1-3.5
Total children (aged 0-15)	30435	1087	31522	11250	2.8	2.3-3.3
Total adults (aged 16 +)	105596	59792	165388	43946	3.8	3.0-4.5

Source: Kavanagh and Opit (1998)

Table 8.2 Average costs (expenditure per unit of activity), £, 1999/2000

	England	Scotland	Wales	Northern Ireland
Occupied hospital bed day	168	132	392	126
Day centre person year	4315	6600	7923	4394
Public sector care home resident year	21283	N/A	47308	27881
Independent sector care home resident year	19446	N/A	32892	20193
Home care per user per year	6037	N/A	11746	2191

Table 8.3: Total costs of supporting people with learning disabilities in 1994, by care setting

Care setting	No. of people	Total costs (1994/95 prices, million)				
		NHS	LASSD	FHSA	Family /DSS	Total
NHS residential care/hospital	21828	879	65	1	15	960
LA social services residential homes	12039	4	525	1	8	266
Voluntary care homes	14538	3	104	1	166	275
Private care homes	15028	6	57	2	167	232
Private ('ordinary') households	103067	70	542	8	756	1376
Total	166500	962	1020	13	1112	3109

Key: NHS = health authority; LASSD = local authority social services department; FHSA = family Health Services Authority; Family/DSS = family or social security payments

Source: Kavanagh and Opit (1998 table 17)

Table 8.4: Mean service package costs for three care settings (£, 1999/2000 price levels)

Service package	Village communities	Residential campuses	Dispersed housing
Number of people in the sample	n=86	n=133	n=281
Total accommodation costs	637	931	902
Day activity costs	125	69	107
Hospital and community services costs	22	17	31
Total service package costs	784	1018	1039

Source: Hallam et al (2004 table 2)

Table 8.5: Average lifetime costs for people with autism

Cost category	Autism with additional learning disability		High-functioning autism	
	Cost (£000)	per cent	Cost (£000)	per cent
Hospital services	27	1	31	4
Other health and social services	72	2	31	4
Living support	2134	73	313	40
Voluntary support	17	1	-	-
Special education	180	6	108	14
Medication	3	<1	8	1
Sheltered work	16	1	68	9
Day activities	422	14	75	10
Lost productivity	-	-	137	18
Family members' time cost	40	1	14	2
Family expenses	31	1	-	-
Total	2941	100	785	100

Source: Jarbrink and Knapp (2001 table 1)