

# 17 Learning Disabilities

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## 1 Summary

### Statement of problem

People with learning disabilities have a wide range of social and health care needs. They may also have coexisting conditions that can contribute to need, including physical or developmental disabilities, mental and physical ill-health and a range of behavioural problems. It is often the presence of these conditions that defines need for services.

The following are basic understandings that should underpin the commissioning and delivery of services.

- People with learning disabilities should be recognised as individuals who have the same citizenship rights as the rest of the population.
- Care is increasingly in the community, and family members often provide the majority of care.
- Most individuals will predominantly need social care services. However, health services play a significant role to ensure that all needs are met.
- Disability may lead to the need for additional and/or specialist support/benefits and services. However, generic services should always be accessible to people with learning disabilities.
- Service planning must be based on partnership working, including health, social care, education, housing, users and their carers. This is particularly important at transition points in people's lives, such as leaving full-time education.
- Service planning and commissioning must include the needs of carers, particularly given the increased life expectancy of many people with learning disabilities and the inevitable ageing of their carers.
- Collaboration between commissioners will be required, as some conditions affect relatively small numbers of individuals within each primary care trust (PCT) population.

### *Policy context*

Central themes in national health care policy include increasing the extent of community-based care and ensuring equivalence of service receipt between subgroups of the population. In order to promote joint working there is a requirement for health and local authorities, with partner agencies, to produce a joint investment plan (JIP) for learning disabilities. Local authorities lead this process. The objective of the JIP should be to 'promote independence and social inclusion'. In 2001, a national strategy for learning disabilities, *Valuing People*,<sup>296</sup> was published by the Department of Health, giving further guidance on the organisation and development of services. It emphasised four key principles – rights, independence, choice and inclusion – that should underpin the way forward.

Analysis of health and social care provision suggests that there is still a significant amount of work needed to ensure that people with learning disabilities have access to high-quality, comprehensive health and social care. Collaboration between commissioners will be essential.

### *Definitions and classification*

The term 'learning disability' commonly refers to a group of individuals with a history of developmental delay, a delay in or failure to acquire a level of adaptive behaviour and/or social functioning expected for their age, and in whom there is evidence of significant intellectual impairment. Many terms are used with little consensus. Classification and terminology are important, both with respect to acceptability to those with learning disability, and also in order to allow accurate communication between those who plan, provide and evaluate services. Lack of standardisation of terms hampers progress. Comparison of research data is difficult, and the translation of research findings to local services, where case-mix may be significantly different, is hard to achieve.

Classification needs to be multi-axial in order to describe the complexity of need. Classification systems generally combine a measure of intellectual functioning (usually intelligence quotient [IQ]) with measures of social and behavioural functioning. The main systems are ICD-10, DSM-IV and the American Association on Mental Retardation Manual of Definitions.

In all, low IQ must be present during the developmental period of life. Other conditions in which IQ is lowered are excluded, e.g. acquired head injuries, schizophrenia and dementia.

The abbreviation 'PWLD' is used here to refer to people with learning disabilities or difficulties.

## **The use of categories**

There is no simple way of categorising PWLD into groups that need a particular service; individual need should dictate the level and type of service input. An individual's social, behavioural and learning abilities must be assessed, in conjunction with measures of intellectual capability. Intellectual impairment refers to a loss of intellectual function. Severe intellectual impairment refers to those with an IQ of < 50 and mild intellectual impairment covers IQs of 50–69 (see Section 3 for discussion of the relationship between intellectual impairment and learning disabilities).

Categories used in this chapter include:

- conditions that are often, or always, associated with intellectual impairment, e.g. Down's syndrome and fragile X syndrome
- impairments/disabilities that occur more frequently in PWLD, e.g. epilepsy and cerebral palsy; developmental disorders, e.g. autistic spectrum disorders (ASD) and mental illness
- losses of function, e.g. hearing and mobility problems
- restriction of participation, e.g. social difficulties with housing or relationships and the impact on carers and families, such as inability to maintain paid employment or to sustain family relationships.

### *Aetiology*

The aetiology of learning disabilities can be subdivided into those conditions that arise at conception (whose prevention lies before conception) and those that arise during pregnancy, labour and after birth. Aetiological agents fall into three main categories: genetic, infective and environmental.

No aetiological cause is found in approximately 30% of cases of severe learning disabilities. The same is true for the majority of cases of mild learning disabilities. Iodine deficiency disease is the commonest cause of severe learning disabilities worldwide. In the UK, the majority of cases are due to genetic factors, non-inherited Down's syndrome and X-linked disorders, such as fragile X, being the most common. Maternal alcohol consumption appears to play a significant role in the development of learning disabilities. It is considered the greatest cause of learning disabilities in the USA, although European research suggests lower figures. Neural-tube defects are also associated with learning disabilities.

## **Prevalence and incidence of learning disabilities and associated conditions**

Some degree of intellectual impairment is relatively common in the general population. A minority of these individuals have severe intellectual impairment. Coexisting medical, psychiatric or other conditions are also common. There has been a steady increase in the prevalence of severe learning disabilities over the past 20 years. This is likely to continue into the next decade. The number who have multiple and complex disabilities will also increase. These trends need to be taken into consideration in service planning.

There are a number of difficulties in arriving at an exact prevalence figure for learning disabilities.

Most population figures for the UK have been determined from service contact, often derived from case registers. This will tend to underestimate overall prevalence. Another consequence is that more is known about those with severe impairment or milder impairment and coexisting conditions (i.e. those in touch with services) than about the much larger group of people with relatively uncomplicated mild or borderline intellectual impairment.

The prevalence of mild intellectual impairment (IQ 50–69) reflects the statistical distribution of IQ in a population and will therefore be in the region of 2.27% of the population. This does not equate with the prevalence of mild learning disabilities. It is likely that those with mild intellectual impairment and additional problems such as challenging behaviours or mental illness will come into contact with services and therefore be identified as having mild learning disabilities. Many individuals with mild intellectual impairment without such problems will not be labelled learning disabled. The population prevalence for mild learning disabilities is estimated to be 1–2% of the population.

Prevalence estimates for severe intellectual impairment (IQ < 50) range from 300–400/100 000 of the general population. All those with an IQ of < 50 will be identified as having severe learning disabilities.

### *Factors that affect incidence and prevalence*

#### **Time trends**

In the UK, successive birth cohorts are of different size. The largest cohort comprises those in their mid-thirties. Analysis of UK case registers suggests that, for adults with IQs of < 50, there has been an increasing prevalence of 1% per year, mainly owing to increases in survival. Projections predict a further increase in the population prevalence of severe learning disabilities of 11% between 1998 and 2008.

**Geography**

There are clear international differences in incidence and prevalence rates, particularly between the developed and developing worlds. It is often assumed that geographic factors have no impact in the UK. However, some authors suggest that there may be regional differences in prevalence, if not in incidence.

**Socio-economic factors**

Some causes of severe learning disabilities are socially determined or influenced. There is, however, little evidence for an effect of social class on the incidence of severe intellectual impairment, though social deprivation is associated with cognitive development. There is some evidence to suggest that there is an increased prevalence of severe learning disabilities in the British Asian population.

*Specific conditions associated with learning disabilities***Down's syndrome**

The frequency of occurrence of Down's syndrome is clearly linked to maternal age. The risk of having an affected child at varying maternal ages is approximately 0.5/1000 when aged 20 years, 10/1000 when aged 40 and 150/1000 when aged 50. The majority of individuals with Down's syndrome have IQs in the range 35–55 and have a higher incidence of medical problems than the general population.

**Fragile X syndrome**

Fragile X syndrome is the most commonly occurring X-linked disorder. Birth frequencies often quoted are 0.8/1000 for males and 0.32/1000 for females, although recent estimates suggest considerably lower figures (0.25/1000 and 0.125/1000, respectively).

**Phenylketonuria**

Phenylketonuria (PKU) is the most common metabolic disorder linked with learning disabilities, with reported birth frequencies of 0.05–0.07/1000 live births.

**Congenital hypothyroidism**

Congenital hypothyroidism is the most common hormonal disorder associated with learning disabilities, with a birth frequency of 0.25–0.3/1000 live births. It is much more common in individuals with Down's syndrome. In the UK, screening and early treatment should ensure that very few cases of PKU or hypothyroidism resulting in severe learning disabilities occur in the UK.

**Epilepsy**

People with learning disabilities have a higher risk of having epilepsy than the rest of the population. This risk increases with severity of impairment, as does the severity of the epilepsy.

**Cerebral palsy**

Cerebral palsy develops in 2–3/1000 live births. Estimates suggest that up to half of those with cerebral palsy will have some difficulties with intellectual functioning, and 23–34% will have an IQ of < 50.

## Mental disorder

Many risk factors known to contribute to the development of mental illness occur more frequently in PWLD. These include sensory impairments, communication difficulties, low self-esteem, stigma, low levels of social support, poor coping skills and chronic ill-health. There is an increased prevalence of psychiatric disorder and behavioural disturbance over that found in the general population. There is considerable difficulty in determining exact figures due to poor detection, misdiagnosis and methodological difficulties.

The occurrence of mental ill-health in children increases with intellectual impairment; 30–42% of 9–11-year-olds with IQs of < 70 were found to require treatment for mental health problems, compared with 6–7% of those with higher IQs.

Estimates of coexisting mental illness and/or behavioural disorder in adults with learning disabilities vary from 14.3–67.3% depending on the methodology and study group. If challenging behaviours are excluded then the rates found fall dramatically. All types of mental disorder are found. Rates of substance misuse and affective disorders found are lower than those in the general population.

Older people with learning disabilities have been shown to have a higher prevalence of mental illness than either the general population or younger age groups of PWLD. This is mainly accounted for by the increase in early dementia, particularly in people with Down's syndrome.

## Challenging behaviours

This term encompasses a diverse group of behaviours, the prevalence of which increases with the severity of intellectual impairment, but differs between groups of PWLD. There is a high prevalence of challenging behaviours in those with ASD, whilst people with Down's syndrome are less likely to demonstrate challenging behaviours.

About 40% of children with an IQ of < 70 display challenging behaviours. Approximately 20 adults with learning disabilities per 100 000 of the total population display behaviours that present a *significant* challenge. Using a broader definition of challenging behaviours, 25% of adults were shown to have behavioural problems that posed a major challenge to the achievement of an ordinary life (approximately 100/100 000). This figure may more accurately reflect the group that will require input from specialist health and social services.

People with learning disabilities seem to be over-represented at all levels of the criminal justice system. Offending behaviours are more likely in those with mild and borderline learning disabilities than in those with the most severe impairment.

## Autistic spectrum disorders

This term refers to developmental disability affecting social and communication skills. Prevalence rates vary according to the diagnostic criteria used. For the whole spectrum, approximately 900/100 000 of the population may be affected. If only those with the most severe disorder are included, then rates are of the order of 40–50/100 000. Autistic spectrum disorders are, overall, about four times more common in boys than in girls. This is most marked in those of higher ability. There is a very strong association with learning disabilities; approximately half of those with severe learning disabilities have some type of autistic spectrum disorder. Autistic spectrum disorders are also strongly associated with challenging behaviours.

### *Losses of function*

Losses of function leading to restriction of activity are common. Sensory impairment, mobility and communication difficulties all occur.

### *Other associated conditions*

Some medical conditions are found more commonly in PWLD, e.g. problems with continence, congenital heart conditions, obesity and some infective conditions, such as hepatitis B. Poor oral health is also common. Improvements in medical care have led to the survival into adulthood and old age of a new cohort of very severely disabled individuals with complex medical needs.

### *Restriction of participation: social consequences*

PWLD often have limited capacity to exercise choice and control over many areas of their lives. This includes where to live, with whom and how to occupy their time. It also applies to choices about service provision. For the majority of PWLD in the community and in residential care, relationships outside immediate family/carers are usually with service providers.

PWLD experience high levels of sexual, physical and emotional abuse. This applies both to those living in their own homes and to those in residential care. Many people with severe learning disabilities have difficulties with activities of daily living.

### **Families and carers**

Caring for a person with learning disabilities can place considerable strain on carers and families, having an impact on emotional well-being, financial resources and relationships.

## **Services available**

A range of health, social and educational services are available – generic services, such as primary care, and specialist learning disabilities services. Services are provided by the statutory and increasingly the voluntary and private sectors. The types of services and service providers vary greatly across the UK. There are gaps in service development across the spectrum of health and social care. It is unlikely that differences in need can explain the pattern of provision that exists.

A key issue in the provision of services is their accessibility. This covers a range of issues, including physical access, information in appropriate formats (e.g. Braille), transport provision, the knowledge and attitudes of staff, and the provision of training and support to generic staff, users and their carers.

### *Primary care*

Primary care services are central to the organisation of adequate health surveillance for PWLD, who have ordinary needs for primary care and special needs relating to the increased rates of certain conditions. There is, however, significant under-detection of both physical and mental ill-health and low uptake of screening and immunisation programmes. Chiropody, continence, dietetics, pharmacy and dentistry services are all needed. Primary care also provides for the needs of families and other carers.

### *Specialist learning disability services*

The majority of PWLD will not need the input of specialist health services. However, those with mild intellectual impairment and coexisting conditions such as mental ill-health and those with severe impairment are likely to need specialist input. The organisation of services varies significantly across the country.

Community learning disability teams (CLDTs) are one of the commonest means of co-ordinating specialist community services for adults with learning disabilities. Most CLDTs in the UK will see people with an IQ of up to 70. There may be gaps in provision for those with higher IQs and associated conditions. There is a need for hospital beds for the assessment and treatment of a small number of PWLD, such as those with mental illness, sensory impairments or challenging behaviour.

Children's services may include input from dedicated teams and paediatric and child and adolescent mental health services. The provision of health services that support transition for disabled people with complex health and support needs has been described as 'very patchy'. The organisation of services for people over 65 with learning disabilities also varies considerably across the country.

Audiology and ophthalmology services with interest and expertise in screening and the fitting of aids for PWLD are needed, as there are high levels of unrecognised morbidity.

### *Accommodation*

Considerable change has occurred in the provision of accommodation – the closure of large institutions, the increasing role of the independent sector, and the acceptance that PWLD should have the opportunity for ordinary life experiences and should be supported to live independently in the community whenever possible. There is significant variation in the type, quality and quantity of residential accommodation across the country. Despite the encouragement of supported living in the community, there are still relatively few PWLD in their own homes or in supported lodgings. The ageing of carers and increasing life expectancy for PWLD will increase future need for a range of accommodation options.

### *Daytime activity*

The capacity to engage in meaningful activity during the day is a key measure of quality of life. This may include paid work, leisure activities and structured day-care programmes. It should be dictated by the needs and desires of the individual. The majority of organised daytime activities are provided by day-care facilities. This is increasingly organised in small community units. Day-care programmes may include centre-based activities, adult education and training and community leisure activities.

### **Employment**

PWLD may be in ordinary employment or a variety of sheltered or supported work schemes. Supported employment schemes have significantly increased in number over the past 10 years. There is, however, uneven distribution across the country and mismatch between supply and demand.

### **Education**

The emergence of education as a key service for both children and, increasingly, adults with learning disabilities has been a marked feature of provision since the 1981 Education Act.

Portage is probably the most common pre-school scheme. Mainstream education increasingly includes children with disabilities, including those with learning disabilities. There is, however, significant variation between LEAs in the rate at which this is being achieved.

The provision of further education seems to have increased for some people with learning disabilities, although those with more severe disabilities may have suffered.

### *Services for mental disorder*

There is a perceived gap in many services in the provision of mental health services for PWLD. This is particularly true for individuals with mild or borderline impairment, for children and the elderly. Most services for adults with learning disabilities and mental illness are associated with specialist learning disability services, with specialist learning disability mental health teams in some areas.

### *Services for challenging behaviours and offending*

A range of specialist day care, inpatient and outpatient services may be provided. Alternatively, general learning disabilities teams cover this group.

There has been a decrease in the number of high-secure hospital beds for PWLD and an increase in medium-secure and other alternative provision. High-secure learning disability services are now centred at Rampton Hospital.

### *Services for autistic spectrum disorders*

A wide range of services is required to meet the diversity of need displayed by both children and adults with ASD. Individuals with ASD require highly structured environments, and services should be organised to provide the familiarity and predictability needed. Children with ASD may attend mainstream education (with or without specialist support), generic special schools, designated units for ASD or receive home-based tuition. Most PWLD and ASD will eventually need some form of residential care. It is often the case that neither adult psychiatric services nor specialist learning disabilities services are set up to provide adequately for those with ASD and higher IQs.

### *Restriction of participation: social consequences*

PWLD may require help to access and understand services and to take an active part in the way in which their care is organised. The development of advocacy services, alongside the provision of interpreters and training for front-line staff in issues relevant to dealing with PWLD, are essential components of adequate service organisation. The development of parenting programmes can also aid independent living.

### **Families and carers**

Families and carers need information, advice, training and support from a range of services. Respite care is a key component in care packages to support carers. It can provide a break for carers, particularly if the client has multiple problems, severe challenging behaviours, or terminal or severe physical illness, and can cover carer illness or other emergencies. Most local authorities have some respite facility, but there is considerable variability in its availability. Family-based rather than residential care is increasingly common.



### *The cost of services*

In 1996, 5% of health and 13% of national social services expenditure was spent on PWLD.

These figures underestimate the total cost, as significant expenditure is not identifiable as being spent on specific care groups. Estimates of total spend are in the region of £3 billion per year.

### **Effectiveness of services**

The determination of effectiveness is challenging for a number of reasons, including differences in research methodologies, the multi-agency and multi-intervention nature of care provided, difficulties in ascertaining the views of PWLD, and the trade-off that may exist between positive outcomes for carers and those that they care for. The literature on the effectiveness of treatments, interventions and service models for PWLD is mainly limited to descriptive and uncontrolled research studies. By far the largest body of work is in the field of accommodation and behavioural interventions.

- Prevention programmes such as genetic counselling for fragile X syndrome, folate supplementation pre and post conception, antenatal screening for Down's syndrome, immunisation and postnatal testing for phenylketonuria and congenital hypothyroidism can all contribute to reducing the incidence and/or severity of learning disabilities.
- An overall measure of the effectiveness of primary and specialist services is the extent to which PWLD have unmet needs for which there are effective interventions. Analysis of the needs of PWLD in the Avon area suggests that many needs are unmet.
- Accommodation – the conclusion often drawn from the available literature is that community-based provision is preferable to hospital care, albeit at a higher cost. However, debate continues about the appropriate mix of alternative provision in terms of scale, the organisation of facilities and the sector of management. Community placements have been associated with improved self-reported outcomes for those individuals who were able to express a view. Longer-term research has demonstrated little change in social functioning and symptomatology one and five years after discharge, although generally at greater cost. Specialist accommodation for individuals with challenging behaviours seems to have better outcomes than hospital-based care.
- Day-centre care is of unknown effectiveness. Evaluation of supported employment schemes has shown positive benefits.
- Psychological interventions, particularly behavioural approaches, can produce changes in behaviours, although long-term sustainability is open to question.
- Antipsychotic medication is commonly used to treat emotional and behavioural disorders in PWLD. Systematic review of randomised controlled trials has provided no evidence as to whether such medication does or does not help adults with learning disabilities and challenging behaviours, or with schizophrenia. Internationally agreed guidelines on the use of psychotropic medication cover issues such as reducing polypharmacy and monitoring.
- In autism there is some evidence from some studies to suggest that the early educational intervention may have benefits.
- Advocacy services are viewed positively by clients. Their overall impact on quality of life or the provision of services is not known.
- Respite care is valued by carers.
- Alternative therapies are also valued by carers and clients and they can contribute to a sense of well-being. There is little evidence to prove or disprove their overall effectiveness or their specific benefits in PWLD.

## Models of care

There is no one model of care that can be recommended, given the diversity of the group and the relative lack of effectiveness information. A systems approach to service provision is necessary if comprehensive, integrated and inclusive services are to be provided. Processes of care, such as the nature of inter-agency working, as well as structural elements will determine the adequacy of local service provision. It is likely that the technical ability of staff will be a greater determinant of local service capacity than the availability of specific settings. It is therefore not possible to examine one element of a service in isolation. It is possible to outline both structural and process components of services that should form the basis for local planning discussions. Local providers and commissioners may then determine the most appropriate local configuration of structure and process needed to achieve a comprehensive service. Local discussion between commissioners and providers will need to cover:

- population need for services
- planning and inter-agency working
- service provision covering health promotion, primary care and specialist learning disability services, daytime activity, accommodation, information and support.

This necessitates partnership working at all levels and between all the relevant agencies. Commissioners of services for PWLD need to recognise the range and complexity of the condition and consequently the inevitable complexity and variability of the system that will be needed to meet their needs. The level at which commissioning is carried out may well be different for discrete aspects of the condition. Individualised packages and joint funding will be needed for those with the most complex needs. Challenging behaviour and sensory impairment services, for example, may well need to be purchased at population levels larger than the average PCT in order to ensure service integrity and expertise. Prevention services and primary care can more easily be provided and commissioned for smaller population groups. The capacity for flexible, local approaches is likely to produce the most comprehensive commissioning and development of services.

## Target setting

The precise nature of local targets will be determined by the current nature of provision and local data collection capabilities. Overall aims should be improvement in quality of life and reduction in social exclusion. Targets can be set with respect to the range of activities and services:

- health promotion: primary and secondary prevention, tertiary prevention – the physical and mental health of PWLD
- accommodation
- daytime activities
- information and support
- specialist services
- commissioning.

For a further discussion of target setting, *see* the All Wales Health Gain Protocol.<sup>2</sup>

## Information and research requirements

### *Data sources*

Routine data sources are limited in their usefulness. The extent to which data can be disaggregated to client group or severity is very variable. Information on a large number of services necessary for comprehensive provision is unavailable, e.g. employment or leisure services. Where local registers have been developed and well maintained, they have been found to be helpful in planning services.

### *Research*

There are significant gaps in research evidence. An extensive research programme is required covering aetiology, epidemiology and effectiveness of service interventions.

## 2 Statement of problem

### Introduction

People with learning disabilities have a wide range of social and health care needs. This reflects the spectrum of severity for learning disabilities and the different conditions that may coexist. People with learning disabilities also have needs generated by social exclusion, such as poverty, lack of housing and unemployment. Those with mild learning disabilities may need specialist support in mainstream education while they are children. Subsequently, they may need the same support/benefits as others in socially excluded groups, rather than specialist services. At higher levels of disability, however, many individuals will have lifelong needs for health and social care.

The coexisting conditions that may contribute to need include:

- physical disabilities, e.g. sensory impairments and mobility difficulties
- mental ill-health across all diagnostic categories
- developmental disabilities, e.g. autistic spectrum disorders (ASD)
- medical conditions, e.g. epilepsy
- a wide range of behavioural problems, from self-injury to inappropriate social behaviours.

This range and diversity of need represent a significant challenge to carers, families and service providers. Planning services is complex, as health, social care, education and housing must all be involved. As learning disability is lifelong, partnership working and the quality of the interfaces between services are crucial. This is particularly true at transition points in people's lives, such as leaving full-time education. The necessity for partnership and collaboration between agencies is emphasised by the knowledge that mental and physical ill-health is often undetected or under-treated (*see* Sections 4 and 5).

People with learning disabilities must be recognised as individuals and treated as having the same citizenship rights as the rest of the population. This means that:

- people with learning disabilities have the same right of access to NHS and other services as the rest of the population
- although disabilities may lead to the need for additional and/or specialist support/benefits and services, generic services should be accessible to everyone
- people with learning disabilities may need help to access services

- individuals should be seen as having health *and* social care needs, not health *or* social care needs (for further discussion of this distinction, *see* Appendix I).

Parents and/or other family members provide the majority of care for people with learning disabilities. Precise figures are not available, but estimates from the old North West Thames Region suggested that the vast majority of individuals between 15 and 24 who were in contact with services (on registers) were cared for by their families. Even up to age 35 a substantial proportion were living in the family home.<sup>1</sup> Many more of those with mild learning disabilities live in their own homes. Service planning and commissioning must therefore include the needs of carers. This is of particular importance given the increased life expectancy of many people with learning disabilities and the inevitable ageing of their carers.

## Policy context

Central themes in national health care policy include increasing the extent of community-based care and ensuring equivalence of service receipt between subgroups of the population. The process of deinstitutionalisation of service provision began in the 1950s. This has led to increasing numbers of people with learning disabilities being cared for in their own homes or non-hospital residential care. The NHS and Community Care Act reinforced the social care emphasis by giving social services the lead for service planning. There remains, however, a significant role for health services, which should meet health needs in all settings. There is considerable scope for both health promotion and health gain.<sup>2</sup>

Policy guidance was released in 1992 as circulars to health and local authorities.<sup>3,4</sup> The Department of Health guidance on continuing care further reinforced the need for agreements between health and social care on their relative responsibilities.<sup>5</sup> In order to promote joint working there is now a requirement for health (now PCTs) and local authorities, with partner agencies, to produce a joint investment plan (JIP) for learning disabilities. Local authorities lead this process. The objective of the JIP should be to 'promote independence and social inclusion' through the promotion of activities such as supported employment, short-term breaks, health screening, and access to education, leisure and other resources available to the general public. In August 2001, a national strategy for learning disabilities, *Valuing People*, was published by the Department of Health, giving further guidance on the organisation and development of services. It emphasises four key principles – rights, independence, choice and inclusion – that should underpin the way forward.

## Commissioning

The very varied rate of resettlement, adequacy of inter-agency working and consequent service development across the country has led to considerable differences in the nature and extent of health provision and funding at local levels. Inter-agency planning must therefore make clear the delineation of responsibilities for all aspects of service provision, so that artificial boundaries between health and social care are diminished.<sup>6,7</sup> Analysis of health and social care provision across 24 authorities suggested that trends in care, such as increased numbers of people living in their own homes, improved levels of day and respite care, and better carer support are occurring or are planned. There is, however, still a significant amount of work needed to ensure that people with learning disabilities have access to high-quality, comprehensive health and social care provision.<sup>8</sup> This is particularly true in relation to primary care and specialist services for those with complex physical and mental health needs.

The effect of the recent changes in the commissioning of health services and the development of primary care trusts (PCTs) is as yet unclear. Some analysis of the impact of GP fundholding suggested little impact on specialist learning disability services.<sup>9</sup> In any given PCT there will be relatively small numbers of

individuals who will require specialist learning disability services. Collaboration between commissioners will therefore be essential.

The Department of Health publications *Signposts for Success* and *Once a Day* give clear advice on the commissioning of health services and the organisation of primary care.<sup>10,11</sup>

## Definitions and classification

The term ‘learning disability’ commonly refers to a group of individuals with a history of developmental delay, a delay in or failure to acquire a level of adaptive behaviour and/or social functioning expected for their age, and in whom there is evidence of significant intellectual impairment.

There are many terms used to classify, categorise and describe the problems and abilities of people with learning disabilities. This is problematic because there is:

*little professional consensus on terminology which has led to transient, culture-specific lay terms being used without discrimination or clear definition.*<sup>12</sup>

In this document, the abbreviation ‘PWLD’ will be used to describe the whole population under consideration. This acknowledges that, in the UK, both ‘people with learning disabilities’ and ‘people with learning difficulties’ are acceptable and commonly used terms, replacing mental handicap and mental retardation.

### Classification systems

Systems used to classify PWLD generally combine a measure of intellectual functioning (usually intelligence quotient, IQ) with measures of social and behavioural functioning.

The main systems are as follows.

- **ICD-10:**<sup>13</sup> F7 – Mental Retardation. This is a bi-axial classification based on IQ (F70 – mild, IQ 50–69; F71 – moderate, IQ 35–49; F72 – severe, IQ 20–34; F73 – profound, IQ < 20) and impairment of behaviour (not further defined). In theory, classification is based on the use of IQ test results to allocate a code. In practice, it is often based on the subjective opinion of the interviewing clinician. This may lead to coding unreliability.  
F84 – Pervasive Developmental Disorders are also relevant. F84 is within Disorders of Psychological Development, F80–89. There are a number of sub-categories, including autism. These conditions deserve specific mention as, unlike other disorders within F80–89, autistic spectrum disorders (ASD) are often inherently associated with major behavioural disorders and, in adults, psychiatric disorder (see ‘Autistic spectrum disorders’ in Section 4 below).
- **DSM-IV:**<sup>14</sup> A multi-axial approach is taken which includes significantly sub-average intellectual functioning (IQ of approximately 70 or less), concurrent deficits or impairments in adaptive functioning, and onset before age 18. Sub-classification is based on severity, reflecting levels of intellectual impairment (IQ scores).
- **American Association on Mental Retardation Manual of Definitions:**<sup>15</sup> Three criteria must be met, namely significantly below average intelligence, deficits in adaptive behaviour (e.g. communication and self-care), and that these should be evident in the developmental period. A sub-classification approach looking at the intensity and provision of support (intermittent, limited, extensive and pervasive) is recommended. The lack of appropriate and precise measuring instruments may hamper use in quantitative research.

In all classification systems, low IQ must be present during the developmental period of life. Other conditions in which IQ is lowered are excluded, e.g. acquired head injuries, schizophrenia and dementia.

### *The use of terms*

Classification should use internationally agreed terms. The International Classification of Impairments, Disabilities and Handicaps (ICIDH) is, however, not routinely used. ICIDH emphasises the importance of the interaction between the individual and their environment, and makes clear distinctions between impairment, disability and handicap.

- **Impairment:** The loss of, or abnormality of, psychological, physiological or anatomical structure or function.
- **Disability:** The restriction of (as the result of impairment), or lack of ability to perform, an activity considered to be within the normal range of human capacity.
- **Handicap:** The disadvantage resulting from impairment or disability that limits or prevents the fulfilment of a role that would be considered normal for that individual.

This classification is currently being revised, moving away from a medical model of disability to a more socially orientated one. The new definitions of the three dimensions are, in the context of a health condition, impairment, activity and participation.

- **Impairment:** The loss or abnormality of body structure or of a physiological function.
- **Activity:** The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
- **Participation:** The nature and extent of a person's involvement in life situations in relation to impairment, activities, health conditions and contextual factors (elements of the environment, e.g. buildings, services and community attitudes).

Individuals who have an impairment of intellectual functioning may have a wide range of restriction of both activity and participation and hence a wide range of needs. This makes a multi-axial approach to classification essential. It is not possible to determine need for services from a simple measure of intellectual functioning. An individual's social, behavioural and learning abilities must be assessed, in conjunction with measures of intellectual capability.

### *Legal terms*

In England and Wales the Mental Health Act 1983 included the terms 'mental disorder' (which includes arrested or incomplete development of the mind), 'mental impairment' and 'severe mental impairment'. These are specific legal terms and as such are not synonymous with mental illness, learning disabilities or intellectual impairment (*see* 'Global categories' in Section 3). Within the Act, severe mental impairment is described as 'a state of arrested or incomplete development of the mind, which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned'. Mental impairment is described as 'a state of arrested or incomplete development of the mind (not amounting to severe mental impairment), which includes etc.'. In the proposed reform of the Act a broader definition of mental disorder is proposed: 'any disability or disorder of mind or brain, whether permanent or temporary, which results in impairment or disturbance of mental functioning'.

Reformed legislation proposes provisions to protect the rights of people with long-term 'mental incapacity' who need care and treatment for serious mental disorder, but who cannot consent to it. There

will be an obligation for a second opinion on the individual's care plan if care and treatment continue for longer than 28 days.<sup>16</sup>

## Conclusions

Planning of services for PWLD requires an understanding of the complexities of need generated by the diversity of the condition and acceptance that social inclusion is a key objective.

Classification needs to be multi-axial in order to describe this complexity of need.

The way in which classification and terminology are used is important, both with respect to acceptability to those with learning disability, and in order to allow accurate communication between those who plan, provide and evaluate services (*see* 'The distribution of intellectual impairment and its relationship to learning disabilities' in Section 4).

## 3 The use of categories

This section describes an approach to categorisation that will be used in this chapter. There is no simple way of categorising PWLD into groups that need a particular service; individual need should dictate levels and type of service input. The aim is to describe groups that need consideration when planning services, rather than to describe service categories.

The global categories describe the difference between intellectual impairment, learning disability and dependency. The partial categories describe groups of health/social impairments/restrictions associated with intellectual impairment which are useful to consider when planning services. The last section describes aetiological groups. These are not generally helpful as a basis for service planning, but form important background understanding.

### Global categories

Fryers describes the following global categories that relate to ICDH.<sup>12</sup>

- **Intellectual impairment:** The loss of function experienced is in relation to the intellect. This is usually expressed by IQ which, although criticised, is widely used. 'Severe intellectual impairment' refers to those with an IQ of less than 50, whilst 'mild intellectual impairment' covers IQs of 50–69. In this chapter, when the term 'severe learning disabilities' is used it refers to those with an IQ of less than 50, 'mild learning disabilities' refers to those with IQs of 50–70 and 'borderline learning disabilities' to those with IQs of up to 80. This is consistent with the common usage of these terms. (For further discussion of the distinction between intellectual impairment and learning disability, *see* 'The distribution of intellectual impairment and its relationship to learning disabilities' in Section 4.)
- **Generalised learning disability:** Strictly speaking, this term should refer to difficulties in learning resulting from intellectual impairment. This is difficult to measure and covers a wide range of disabilities, not all related to IQ. In the UK, the term 'learning difficulty' is often used within the education system to refer to a wide range of learning disabilities. Specific difficulties, such as dyslexia, are included with more generalised learning disability. In educational practice, the term 'learning disabilities' is usually used to refer to those with an IQ of less than 70.

- **Generalised dependency:** Intellectual impairment may produce a range of handicaps which lead to dependency. The range of handicaps is determined by the severity of impairment and other factors, such as coexisting conditions and societal attitudes. If society gives high regard to the ability to read, for example, the inability to do so will be a significant handicap.

## **Partial categories**

Fryers also describes 'partial categories'. They are described as partial because they are not simply sub-categories of the more general categories described above. There is overlap between intelligence and learning categories. For example, individuals with ASD, who are not intellectually impaired, may still have some degree of learning disability. These partial categories have been adapted slightly and are described below.

### *Physical impairments: aetiological and pathological groups*

There are a large number of identifiable conditions, mainly secondary to chromosomal abnormalities, that are often or always associated with learning disabilities, such as Down's syndrome and fragile X syndrome. Some organic impairments are part of syndromes that include intellectual impairment, e.g. fetal alcohol syndrome. Many of these conditions are rare, and only the most common are discussed further.

### *Syndromes of impairments and/or disabilities*

This covers impairments and disabilities, such as epilepsy and cerebral palsy, mental illness and developmental disorders, e.g. ASD. Challenging behaviours are also included here, although they are less well defined. These conditions all occur more frequently in PWLD. They may be found together with any underlying aetiology, although some associations are more common than others, e.g. fragile X syndrome and ASD.

### *Specific restriction of activities: losses of function*

PWLD have higher frequencies of specific motor and sensory disabilities, such as hearing and mobility problems.

### *Restriction of participation: social consequences*

This refers to the social difficulties PWLD may experience, such as lack of housing and employment or limited relationships and social support networks.

### *Restriction of participation: carers and families*

Families and carers of PWLD may experience significant restriction of participation because they are unable to maintain paid employment or to sustain family relationships, for example.

## **Aetiology**

The aetiology of learning disabilities can be subdivided into conditions that arise at conception (whose prevention lies before conception) and those that arise during pregnancy, labour and after birth (see Table 1).<sup>17</sup> Aetiological agents fall into three main categories: genetic, infective and environmental.



No aetiological cause is found in approximately 30% of cases of severe learning disabilities. The same is true for the majority of cases of mild learning disabilities. There is still considerable scope for preventative work, despite incomplete understanding of aetiology (see 'Health promotion' in Section 6).

**Table 1:** Major aetiological factors that cause learning disabilities.

Aetiological factor	Timing of injury/exposure		
Genetic	<b>Antenatal</b>		
	<b>Chromosome aberrations</b>	<b>Secondary neurological damage</b>	
	<ul style="list-style-type: none"> <li>• Trisomies:               <ul style="list-style-type: none"> <li>– 21: Down's syndrome</li> <li>– 18: Edwards' syndrome</li> <li>– 13: Patou syndrome</li> </ul> </li> <li>• Sex-linked, e.g. fragile X syndrome</li> </ul>	<ul style="list-style-type: none"> <li>• Disorders of:               <ul style="list-style-type: none"> <li>– protein metabolism, e.g. phenylketonuria</li> <li>– lipid metabolism, e.g. Tay-Sachs</li> <li>– carbohydrate metabolism</li> <li>– mucopolysaccharide metabolism, e.g. Hurler's syndrome</li> <li>– hormone system, e.g. congenital hypothyroidism</li> </ul> </li> </ul>	
	<b>Antenatal</b>	<b>Perinatal</b>	<b>Postnatal</b>
Infective	<ul style="list-style-type: none"> <li>• Rubella – damage more severe, the earlier in pregnancy contracted</li> <li>• HIV</li> <li>• Toxoplasma</li> <li>• Cytomegalovirus</li> </ul>	<ul style="list-style-type: none"> <li>• Herpes simplex</li> </ul>	<ul style="list-style-type: none"> <li>• Meningitis</li> <li>• Encephalitis</li> <li>• Encephalopathies, e.g. measles</li> <li>• Whooping cough – secondary to brain injury</li> </ul>
Environmental	<ul style="list-style-type: none"> <li>• Nutritional deficiencies, e.g. iodine</li> <li>• Rhesus incompatibility</li> <li>• Drugs/alcohol</li> <li>• Irradiation</li> </ul>	<ul style="list-style-type: none"> <li>• Birth injury:               <ul style="list-style-type: none"> <li>– trauma</li> <li>– hypoxia</li> <li>– hypoglycaemia</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Trauma: accidents and non-accidental injury resulting in head injury</li> <li>• Lead</li> <li>• Nutrition</li> </ul>

### Genetic factors

Iodine deficiency disease is the commonest cause of severe learning disabilities worldwide. In the UK, the majority of cases are due to genetic factors. Non-inherited Down's syndrome causes approximately 30% of cases at birth. The second most common known cause is X-linked disorder, most commonly fragile X syndrome. Other single-gene disorders, of which more than 2000 have been identified, account for 12% of cases. Known genetic disorders cause only 5–10% of cases of mild learning disabilities, although more are being recognised.<sup>18,19</sup>

### *Non-genetic factors*

Ante- and postnatal factors such as infection, non-accidental injury and accidents cause approximately 25% of severe learning disabilities. Obstetric complications and birth injury cause about another 10%. This accounts for some of the observed association between learning disabilities, epilepsy and cerebral palsy, low birth weight also being an important factor.<sup>20</sup>

Infective causes are uncommon and outcome is very variable. Rubella infection in early pregnancy severely affects the development of those who survive; later infection tends to be less damaging. Toxoplasma and cytomegalovirus infections can also cause impairment. Antenatal HIV infection may cause delay in cognitive development that requires educational support in mainstream schools in about a quarter of children.<sup>21</sup>

Maternal alcohol consumption is considered to be the leading cause of learning disabilities in the USA. European research gives lower figures.<sup>22,23</sup>

Neural-tube defects (NTDs) and other central nervous system malformations, such as microcephaly, are associated with learning disabilities. Dietary folate deficiency is associated with an increased risk of NTDs. A small number of cases have a genetic basis.

## **Conclusions**

The recognition of intellectual impairment and the diagnosis of identifiable causes and associated physical and other impairments/disabilities are fundamental issues necessary for both the planning and evaluation of services. Appropriate classification and terminology should underpin these processes. The lack of standardisation of terms hampers progress across research, service planning and provision. Comparison of research data is difficult and the translation of research findings to local services, where case-mix may be significantly different, is hard to achieve. It is often the case that IQ is the only measure available with which to compare research findings.

In this chapter, learning disabilities as an overall group are discussed and, where appropriate, partial categories. There is also discussion of specific age groups (children, adults and older people) as necessary.

## **4 Prevalence and incidence of learning disabilities and associated conditions**

This section describes what is known about the prevalence and incidence of learning disability and some of the conditions with which it commonly coexists.

There are a number of difficulties in arriving at an exact prevalence figure for learning disabilities. This is for the following reasons.

- The social construction of underlying concepts has varied over time.
- There is a wide spectrum of disorder.
- Definitions are not standardised (*see* 'Definitions and classification' in Section 2).
- Incidence and prevalence have changed over time.
- Service utilisation research methodologies are common and limit the population studied to those in touch with services.

## The distribution of intellectual impairment and its relationship to learning disabilities

Most population figures for the UK have been determined from service contact, often derived from case registers. For the following reasons, these underestimate the true prevalence of learning disabilities and coexisting conditions.

- Delay in diagnosis skews case finding so that prevalence appears higher in 15–19-year-olds than in young children; case ascertainment is more complete with increasing age, as milder degrees of impairment are more likely to be identified later.
- Those with severe impairment, or with significant other disabilities/coexisting conditions, are more likely to use services and so be registered as a service contact.
- Many coexisting conditions remain unrecognised/undiagnosed.
- Data accuracy and completeness depend on the adequacy of local inter-agency working and the development of local information systems.

As a consequence, more is known about people with either severe impairment or mild impairment and coexisting conditions (i.e. those in touch with services) than about the much larger group of people with relatively uncomplicated mild or borderline intellectual impairment.

### *Mild intellectual impairment (IQ 50–69)*

The number of individuals with mild intellectual impairment reflects the statistical distribution of IQs in a population around an arithmetic mean. IQ tests were standardised around a mean of 100. If this is taken to be the mean for a population, then 2.27% will have an IQ of less than 70, with a slight increase over the statistical distribution for IQs of less than 50, where specific pathologies come into play.

The terms ‘mild intellectual impairment’ and ‘mild learning disabilities’ are not equivalent. There is large variation in how the latter group is selected, i.e. it will vary between researchers, services, carers, etc. Societal and professional attitudes, service structures and legislation will determine selection and therefore prevalence figures. This results in wide variation in prevalence figures for mild learning disabilities. It is more likely that individuals with mild intellectual impairment and challenging behaviours or mental illness will come into contact with services and therefore be identified as having mild learning disabilities. There will, however, be many individuals with this level of intellectual functioning who are not in contact with services and who will not be labelled learning disabled. Estimates for prevalence of mild learning disabilities, i.e. those identified as having needs or problems, as opposed to all those with mild intellectual impairment, i.e. with an IQ of less than 70, will vary depending on definition. The population prevalence for mild learning disabilities is estimated at 1–2% (10–20/1000) of the population, whilst mild intellectual impairment will affect 2–3% (20–30/1000).<sup>24,25</sup>

### *Severe intellectual impairment (IQ of less than 50)*

The commonly quoted prevalence for severe impairment is 3–4/1000 of the general population. There is a slight preponderance of males over females. All those with an IQ of less than 50 will be identified as having severe learning disabilities. Analysis of the Leicestershire case register gives a prevalence for severe intellectual impairment of 3.44/1000 and for severe learning disabilities of 3.95/1000. The latter group was defined as those in need of learning disability services, i.e. notified to the register. This definition of

severe learning disabilities therefore includes those with severe intellectual impairment (IQ of less than 50) and those with mild/borderline impairment (IQ greater than 50) who have other conditions, such as mental illness, ASD or challenging behaviours, who need services.<sup>26</sup>

Table 2 shows the estimated age-specific prevalence for severe impairment.

**Table 2:** Estimates of age-specific prevalence for severe intellectual impairment in the UK.

Age (years)	Prevalence/1,000 population		
	1990	1995	1998
0–4	2.50	2.00	1.75
5–9	3.00	2.25	2.00
10–14	4.00	2.75	2.25
15–19	4.50	3.50	3.00
20–24	5.00	4.00	3.75
25–29	4.50	4.50	4.25
30–34	4.00	4.00	4.50
35–39	3.50	3.75	4.00
40–44	3.00	3.25	3.50
45–54	2.50	2.75	3.00
55–64	2.00	2.25	2.50
65–74	1.00	1.25	2.00
75+	Very few	1.0	1.25

These estimates refer to a nominally distributed population in a stable district with no local factors which would significantly affect the prevalence of severe intellectual impairment. Therefore local relevant population variables should be taken into consideration before applying these figures.

Source: Fryers.<sup>17</sup>

## Factors that affect incidence and prevalence

### *Time trends*

It is suggested that, in the developed world, the incidence and prevalence of severe learning disabilities increased up until the mid-1960s, with decreases into the 1980s, albeit to a level that was still twice that in the 1960s.<sup>17,26</sup> This is thought to be the result of a complex series of changes, some of which increase incidence and prevalence, while others decrease them. These changes include:

- an overall decrease in the numbers of young children since the late 1960s
- the impact of oral contraception on conceptions in older women, i.e. those associated with the greatest risk of chromosomal abnormality
- antenatal screening for Down's syndrome, amniocentesis for older women and selective termination
- availability of neonatal care and consequent decreases in early mortality, particularly of low and very low birth weight babies
- new technologies, e.g. new anticonvulsants and advances in cardiac and gastrointestinal surgery, alongside improvements in general medical care leading to increased long-term survival

- immunisation programmes which decreased encephalitis, encephalopathies and rubella-associated prenatal damage.

As a result, in the UK, successive birth cohorts are of differing size, which in turn means that as each cohort ages, the age-specific prevalence varies accordingly (see Table 2). Currently, individuals in the largest cohort are aged in their mid-thirties.

Analysis of UK case registers suggests that, for adults with IQs of less than 50, there has been an increase in prevalence of 35% over the period 1960–95 (approximately 1% per year).<sup>26</sup> Projections based on the Leicestershire case register predict a further increase in the population prevalence of severe learning disabilities of 11% between 1998 and 2008. This is largely as a result of improved survival, especially into old age.

### *Mortality*

PWLD have an increased risk of early death. The risk of dying before the age of 50 has been found to be 58 times greater than in the general population.<sup>27</sup> Life expectancy diminishes with severity of impairment. For those with mild impairment, rates differ little from the general population. Other predictors of early mortality include inability to walk, cerebral palsy, incontinence, residence in hospital and other coexisting medical problems, such as epilepsy.<sup>28–30</sup> The leading cause of death recorded in a London-based study was respiratory disease (52%, compared with 15% in the general population).<sup>27</sup> This finding, if not a recording bias, may indicate suboptimal treatment, in conjunction with a greater incidence of underlying pathology. A healthy survivor effect seems to exist; for the severely impaired aged over 50 years mortality approaches the mean.<sup>27</sup>

### *Socio-economic factors*

Some causes of severe learning disabilities are socially determined or influenced (see 'Aetiology' in Section 3). There is, however, little evidence for an effect of socio-economic background on the incidence of severe intellectual impairment. Long-term cohort studies have nevertheless found a consistent effect of social class on cognitive development.<sup>31</sup> The incidence of cerebral palsy is also associated with socio-economic deprivation. Possible explanations for this include poor nutrition and low uptake of screening programmes and antenatal care.

### *Ethnicity*

There is some evidence to suggest that there is an increased prevalence of severe learning disabilities in the British Asian population.<sup>32</sup>

### *Geography*

There are clear international differences in incidence and prevalence rates, particularly between the developed and developing worlds. It is often assumed that geographic factors have no impact in the UK. However, some authors suggest that there may be regional differences in prevalence, if not incidence.<sup>33,34</sup> This may reflect socio-demographic factors and/or local service issues, such as the closure of large institutions and the availability of independent-sector provision.

## Physical impairments: aetiological and pathological groups

### *Down's syndrome (trisomy 21)*

The frequency of occurrence of Down's syndrome is clearly linked to maternal age. The risk of having an affected child at varying maternal ages is approximately 0.5/1000 when aged 20 years, 10/1000 when aged 40 and 150/1000 when aged 50.<sup>35</sup> The expected birth prevalence of Down's syndrome per 1000 live births increased from 1.67 in 1996 to 1.84 in 1998. The observed birth prevalence was 0.91/1000 live births in 1996 and 1.04/1000 live births in 1998.<sup>36</sup> The prevalence will be determined by rates of conception in differing maternal age groups and the impact of screening programmes (*see* 'Secondary prevention' in Section 6).

The majority of individuals with Down's syndrome have IQs in the range 35–55; 10% have an IQ of less than 20. People with Down's syndrome have a higher incidence of medical problems than the general population; 30–45% have congenital heart disease, 6% have gastrointestinal anomalies, 1% develop childhood leukaemia, there is an increased incidence of hypothyroidism, the majority of individuals develop early-onset dementia, 70% have hearing problems, 50% have sight difficulties and many have increased levels of severe periodontal disease.<sup>37,38</sup> The prevalence of behavioural problems is less than that seen in other groups with severe learning disabilities, although greater than in the general population.<sup>39</sup>

There is differential mortality between people with Down's syndrome and other groups with intellectual impairment. Rates are similar up to the early thirties, but over 35 years, rates are significantly higher for Down's syndrome. This may be the result of the increased incidence of early dementia, cardiac conditions and cancer in people with Down's syndrome. Approximately half of those with Down's syndrome live until the age of 60.

Antenatal screening for Down's syndrome is routine practice in the UK (*see* 'Secondary prevention' in Section 6).

### *Other trisomies*

Trisomies 13 and 18 also occur (Patou syndrome and Edwards' syndrome). The birth frequencies are of the order of 0.25 and 0.3/1000, respectively, increasing with maternal age.

### *X-linked disorders*

Fragile X syndrome is the most common X-linked disorder. There is continued debate over birth frequencies. Figures often quoted are 0.8/1000 for males and 0.32/1000 for females, though they may actually be considerably lower at 0.25/1000 and 0.125/1000, respectively.<sup>40,41</sup> About 6% of those with learning disabilities tested in institutions have the condition.<sup>42</sup>

Most affected males have IQs of less than 50, although there is a wide range in recorded IQs. Many will therefore need extra help at school and protected employment later. Only 30% of women with fragile X have the condition; the rest are carriers. Affected females usually have borderline or normal IQs, but most have some learning difficulties. Fragile X is associated with an increased risk of other conditions such as ASD and congenital cardiac abnormalities. The relationship between ASD and fragile X is not clear; there is a higher frequency of autistic traits in fragile X than in other groups with learning disabilities.<sup>43</sup>

There is no direct evidence of any great benefit from early diagnosis. Screening for the disorder is possible, but there is no national programme (*see* 'Primary prevention' in Section 6).

Other X-linked disorders, e.g. triple X and XXY (Klinefelter's syndrome), each occur in approximately 1/1000 of all live births. Individuals show a range of IQs, usually low normal or mildly impaired, and many will have learning difficulties.<sup>44</sup>

### *Metabolic disorders*

Disorders of protein, lipid, carbohydrate or mucopolysaccharide production all occur. They are all rare. Phenylketonuria (PKU) is the most common disorder, with a birth frequency of 0.05–0.07/1000 live births. It is a single-gene recessive disorder, which usually results in severe impairment if untreated by dietary restriction. The current screening programme should ensure that virtually no new cases with learning disabilities occur in the UK (*see* ‘Secondary prevention’ in Section 6).

### *Hormonal disorders*

Congenital hypothyroidism is the most common hormonal disorder linked with learning disabilities, with a birth frequency of 0.25–0.3/1000 live births. It is much more common in individuals with Down’s syndrome. Intellectual functioning varies, but is severely impaired unless treatment is started early. As with PKU, screening should ensure that very few new cases with learning disabilities occur in the UK (*see* ‘Secondary prevention’ in Section 6).

## **Syndromes of impairments and/or disabilities**

Epilepsy, cerebral palsy and neural-tube defects are discussed in this subsection. As there are a number of mental disorders they are discussed separately in the subsections on ‘Mental disorders’, ‘Challenging behaviours’, ‘Offending behaviours’ and ‘Autistic spectrum disorders’ below.

### *Epilepsy*

People with learning disabilities have a higher risk of having epilepsy than the rest of the population. This risk increases with severity of impairment, as does the severity of the epilepsy. The risk of active epilepsy in the general population is 0.5%. For those with an IQ of 50–70 it is approximately 4%, for those with IQ of 20–50 it is 30%, and 50% of those with an IQ of less than 20 have had at least one seizure.<sup>45</sup> Epilepsy is more likely in cases of intellectual impairment associated with peri/postnatal brain injury.

There is debate as to whether the coexistence of learning disabilities and epilepsy leads to an increased risk of mental disorder. Some research suggests that this is not the case, if IQ and other factors are controlled for.<sup>46</sup>

Seizures are a significant cause of excess mortality in PWLD.

### *Cerebral palsy*

Cerebral palsy develops in approximately 2–3/1000 live births.<sup>47</sup> Estimates suggest that up to half of those with cerebral palsy will have some difficulties with intellectual functioning and between 23% and 34% will have an IQ of less than 50.<sup>18,48</sup> In the UK, approximately 92–136/100 000 of the population have severe learning disabilities and cerebral palsy. This proportion is likely to increase with advances in neonatal medicine. The risk of cerebral palsy and severe learning disabilities increases with prematurity and low birth weight.

Physical disabilities are commonly associated with cerebral palsy. Half of those with cerebral palsy and severe learning disabilities also have epilepsy, 65% are immobile, 60% have severely limited manual dexterity and 60% have impaired vision.

### *Neural-tube defects (NTDs)*

In the mid-1990s the incidence of anencephaly was estimated at approximately 0.3/1000 births (this includes all affected infants, whether live or still births, and pregnancy termination for NTDs) and 0.38/1000 for spina bifida.<sup>49</sup> Intellectual impairment is associated with NTDs. Screening is routine practice in the UK (see 'Secondary prevention' in Section 6).

## **Mental disorders**

The prevalence of psychiatric disorder and behavioural disturbance is higher in all age groups of PWLD than in the general population. There is considerable difficulty in determining exact figures for the reasons listed below.

- **Poor detection:** This may arise from communication difficulties, because of lack of speech or appropriate vocabulary. Carers and relatives may not understand the signs of mental distress/illness, e.g. behavioural changes. Similarly, professionals may ascribe abnormal behaviours to the underlying intellectual impairment rather than make a diagnosis of mental illness.
- **Misdiagnosis:** This may also result from the above factors, e.g. depression may be mistaken for dementia or schizophrenia for autism. Concurrent physical ill-health may make diagnosis more difficult.
- **Medication:** The effects of medication may confuse the clinical presentation of mental illness.
- **Methodological issues:** Comparison between studies, and extrapolation of results, may be difficult because of differences in definition, case-mix and diagnosis, e.g. the inclusion or not of challenging behaviours. There is also uncertainty about the applicability of established systems of psychiatric diagnosis to those with severe intellectual impairment.<sup>50</sup>

The aetiology of mental illness in PWLD is, as in the general population, usually multi-factorial. Social, environmental and biological factors all have a potential impact on the development of disorder. Many risk factors known to contribute to the development of mental illness occur more frequently in PWLD. These include sensory impairments, communication difficulties, low self-esteem, stigma, low levels of social support, poor coping skills and chronic ill-health. Some causes of intellectual impairment are risk factors in their own right, e.g. Down's syndrome for dementia and fragile X syndrome for ASD.

### *Mental ill-health in children with learning disabilities*

The frequency of mental ill-health in children increases with severity of intellectual impairment. In the Isle of Wight studies, 30–42% of 9–11-year-olds with IQs of less than 70 required treatment for mental health problems, compared to 6–7% of those with higher IQs.<sup>51</sup> A Swedish study of 13–17-year-olds showed 57% of children with IQs of 50–70 and 64% of those with IQs of less than 50 had diagnosable mental disorder, compared to 5% of controls.<sup>52</sup> In South East London, 47% of children under 16 with an IQ of less than 50 had a psychiatric disorder.<sup>53</sup>

The prevalence of anxiety and phobic states, depressive syndromes, conduct disorder and eating disorders seems to increase as IQ increases. This may result partly from difficulties in case ascertainment if communication skills are limited and/or disability prevents the expression of certain behaviours, e.g. overactivity will be restricted if mobility is limited.



### *Mental ill-health in adults with learning disabilities*

Estimates of coexisting mental illness and/or behavioural disorder in adults with learning disabilities vary from 14.3% to 67.3%.<sup>54</sup> If challenging behaviours are excluded then the rates found fall dramatically.<sup>55</sup> The pattern of ill-health is somewhat different to that found in the general population. Higher rates of substance misuse and affective disorders are found in the general population.<sup>56</sup>

- **Affective and anxiety disorders:** Some studies suggest that the rates of affective disorders are lower in adults with learning disabilities than in the general population. Poor detection and misdiagnosis may account for some of this observed difference.<sup>57,58</sup> There may also be differences between those with Down's syndrome and other PWLD.<sup>59</sup>
- **Schizophrenia:** Studies suggest that the prevalence of schizophrenia in those with learning disabilities may be 3–4 times higher than in the general population. Accurate diagnosis, however, is difficult in those with severe impairment, particularly if communication is limited.<sup>60</sup>
- **Dementia:** The prevalence of dementia is higher in people with severe learning disabilities (*see* 'Mental ill-health in older people with learning disabilities' below).
- **Adjustment reactions:** PWLD may be more vulnerable to adverse life events and consequently suffer adjustment disorder more commonly than the general population. The significance of life events such as bereavement, for PWLD is often not recognised.<sup>61</sup>
- **Post-traumatic stress disorder:** PWLD suffer high levels of abuse and are therefore at greater risk of post-traumatic stress disorder.

### *Mental ill-health in older people with learning disabilities*

Older people with learning disabilities have a higher prevalence of mental illness than either the general population or younger PWLD.<sup>62</sup> This is mainly the result of a small increase in anxiety and depression and a significant increase in dementia, particularly in people with Down's syndrome. A London study showed that 70% of people with Down's syndrome over the age of 50 had clinical signs of dementia.<sup>63</sup> In people with moderate to severe learning disabilities of mixed aetiology, 11.4% of those over 50 years had dementia.<sup>64</sup>

## **Challenging behaviours**

There are a variety of definitions of challenging behaviours. The following is a broad definition that encompasses diverse behaviours, such as self-injury and stereotypy in people with severe intellectual impairment, and offending in those less severely affected:

*culturally abnormal behaviour/s of such intensity, frequency or duration that the physical safety of the person or others is likely to be put in some serious jeopardy, or behaviour that is likely to seriously limit the use of, or result in the person being denied access to ordinary community facilities (this excludes behaviours which are caused by psychiatric disorder).*<sup>65</sup>

Other terms, such as 'interactional challenge', have been coined in an attempt to reduce stigma. This concept emphasises the primacy of the interaction between the environment and the individual.<sup>66</sup>

Challenging behaviours are not spread evenly through the population of PWLD. There is a high prevalence of challenging behaviours in people with ASD, whilst people with Down's syndrome are less likely to demonstrate challenging behaviours.<sup>39</sup> Some genetic conditions are associated with specific abnormal behaviours, e.g. Lesch-Nyhan's syndrome with self-injury, particularly of oral tissues, hypercalcaemia with hyperactivity and Prader-Willi's syndrome with overeating.<sup>67</sup> Alternatively, associated

conditions, such as sensory impairment, pain or communication difficulties, may lead to changes in or challenging behaviour. This can create diagnostic difficulties. For example, visual impairment may lead to depression or challenging behaviours and be misdiagnosed as dementia or schizophrenia.

### *Challenging behaviours in children with learning disabilities*

Challenging behaviours increase with the severity of intellectual impairment.<sup>68,69</sup> Estimates suggest that about 40% of children with an IQ of less than 70 display challenging behaviours, including overactivity, severe tantrums and self-injury.

### *Challenging behaviours in adults with learning disabilities*

About 20 adults with learning disabilities per 100 000 of the whole population display behaviours that present a significant challenge.<sup>70</sup> As in children, the prevalence of challenging behaviours increases with the severity of impairment; 60% of people with severe impairment show some stereotypic behaviour. Analysis of the Leicestershire Learning Disabilities Register, using a broader definition of challenging behaviours (including significant risk from accidents and stress to carers, for example), suggested a higher figure. A quarter of adults on the register had behavioural problems that posed a major challenge to the achievement of an ordinary life (approximately 100/100 000).<sup>26</sup> This figure may more accurately reflect the group that need specialist health and social service provision. Self-injurious behaviour was also found to be common; 17% of adults on the Register self-injured.<sup>71</sup>

Reported variation in local prevalence may be at least partly accounted for by the differences between settings. Prevalence is generally highest in hospital residents.<sup>72</sup>

PWLD and challenging behaviours often have additional health and social problems. In one study, 24% had restricted mobility, 38% were not fully continent and 70% required assistance with washing.<sup>73</sup>

## **Offending behaviours**

Risk factors for offending include mild/borderline learning disabilities, youth, low socio-economic status, poor parenting experience and early institutionalisation.<sup>74</sup>

Overall, it is suggested that there are:

- high numbers of offenders with mild and borderline learning disabilities<sup>75</sup>
- increased levels of offending amongst those with mild and borderline learning disabilities
- lower levels of offending amongst people with severe and profound learning disabilities
- differences in the quality of offending between people with mild learning disabilities and those with more severe learning disabilities; the former are more likely to commit violent crimes that require planning or complex skills<sup>76</sup>
- high levels of mental illness and/or substance misuse in offenders with learning disabilities
- probable increased rates of arson and sexual offences amongst offenders with learning disabilities, although bias in court referral to hospital may skew this picture<sup>77</sup>
- higher levels of recidivism amongst offenders with borderline learning disabilities.

Offending behaviour in PWLD is sometimes treated as a form of challenging behaviour and may consequently be decriminalised. Despite this, people with learning disabilities seem to be over-represented at all levels of the criminal justice system. This may be partly explained by a higher risk of detection. UK studies suggest that between 5% and 9% of people taken to police stations for questioning had used learning disabilities services in the past.<sup>78,79</sup>

## Autistic spectrum disorders

This term refers to developmental disability that affects social and communication skills. All types of ASD share the following behavioural criteria, regardless of diagnostic sub-type or level of ability:<sup>80,81</sup>

- qualitative impairment in reciprocal social interaction
- qualitative impairment in verbal and non-verbal communication
- markedly restricted repertoire of activities and interests.

Reported prevalence rates vary according to the diagnostic criteria used. The earliest studies used Kanner's narrow criteria of elaborate repetitive routines, aloofness and indifference to others.\* This gave rates of 20–50/100 000, depending on how strictly criteria were applied. Rates are significantly higher if the whole autistic spectrum is considered.† This includes individuals with the triad of behavioural criteria cited above, however they are manifested. Children who make positive but socially inappropriate approaches to others are included, as well as those who are aloof and indifferent. Some of those in the spectrum fit the syndrome described by Asperger in 1944 or that described by Wolf in 1995, 'schizoid personality disorder of childhood'.‡ It is now considered that there is overlap between these syndromes, which represent the most able end of the autistic spectrum. The only studies covering the whole spectrum are those by Wing and Gould, in which almost all of the subjects had IQs of less than 70, and Ehlers and Gilberg, who studied children in mainstream education with IQs of 70 or above.<sup>82,83</sup> The total prevalence combining these two studies is 910/100 000. The numbers in these studies were small and therefore caution should be attached to this estimate. Further research is required, particularly as some reports suggest that the number of cases is increasing, and there is controversy about reported links to MMR vaccination.

Autistic spectrum disorders are overall about four times more common in boys than in girls. This difference is most marked in those of higher ability, being much less marked in individuals with severe or profound learning disabilities.

The proportion of people with ASD and learning disabilities also depends on the diagnostic criteria used. The early studies of Kanner's syndrome suggested that one third had severe learning disabilities, one third had mild learning disabilities and one third were in the average or high range for IQ. The proportion is, however, higher if the whole spectrum of ASD is considered. Whatever criteria are used, it is clear that there is a very strong association with learning disabilities. Approximately half of those with severe learning disabilities have some type of autistic spectrum disorder.<sup>84</sup>

Autistic spectrum disorders are also strongly associated with challenging behaviours. Most individuals with severe learning disabilities and challenging behaviours also have ASD. Small proportions of more able

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\* The original description of Kanner's syndrome in 1943 consisted of the following features: a profound lack of affective contact with people, an anxious obsessive desire for the preservation of the sameness in the child's routine and environment, a fascination for objects, which are handled with skill in fine motor movements, mutism or a kind of language that does not seem intended for interpersonal communication, feats of memory or skills on performance tests and onset from birth or before 33 months. These were later modified so that two criteria were thought to be essential, namely profound lack of affective contact and repetitive, ritualistic behaviour, which must be of an elaborate kind.

† There is no really clear distinction between classical autism and the rest of the spectrum. Hence a dimensional rather than categorical approach is most appropriate. Generally, classical autism is most like that described by Kanner, only rather wider.

‡ Asperger's syndrome was first described in 1944, based on the case histories of a group of children with unusual patterns of behaviour, which included being socially odd, naive and emotionally detached, lacking common sense and good speech – which was often used for monologues rather than reciprocal conversation, and having borderline, normal or superior IQs, and circumscribed interests in specific subjects.

people with ASD commit crimes. This may be due to the pursuit of unusual special interests, e.g. fire setting, guns or other weapons, lack of understanding of social rules, e.g. making social advances to someone in the street, or continuing anger because of past teasing or bullying. A recent study suggested that around 2% of people in high-secure hospitals have ASD.<sup>85</sup>

The spectrum is also associated with epilepsy. Between one quarter and one third of those with typical autism will have at least one fit by the time they reach adulthood. This risk is increased for those with severe learning disabilities.

## **Specific restriction of activities: losses of function**

### *Mobility*

Of all those with severe learning disabilities, 15% have difficulty walking and 10% are unable to walk.<sup>86</sup>

### *Sensory impairments*

Sensory impairments are common.

- **Sight:** Up to 30% of PWLD may have significant impairment of sight, whilst 10% are blind or partially sighted.<sup>87</sup> Three quarters of people with learning disabilities have refractive errors. There are particularly high levels of visual problems in those with Down's syndrome and fragile X syndrome. Up to 60% of people with Down's syndrome have acquired cataracts.
- **Hearing:** The reported prevalence of hearing impairment is in the range 22–68%, depending on the population studied. About 7% are deaf or partially deaf.<sup>88</sup> There are a number of different causes, e.g. congenital problems, recurrent infections or impacted earwax. Hearing deteriorates at a faster rate in people with Down's syndrome than in the general population or in other people with learning disabilities.

### *Communication*

Many PWLD will have impairment of communication or social ability. Population estimates for the extent of such difficulties are not available. In the UK OPCS Disability Survey conducted during the 1980s, at least 50% of adults identified as having learning disabilities (in both communal establishments and private households) found it difficult to either understand or be understood by strangers.<sup>89</sup> The survey covered people with more severe learning disabilities, owing to the way cases were identified.

### *Multiple disabilities*

Improvements in medical care have led to the survival into adulthood and old age of a new cohort of very severely disabled individuals with complex needs. The numbers of individuals in any one PCT may be small, but their support needs are significant. They often require complex support packages, which include technologies such as gastrostomy feeding, suction or nebulisers.

## **Specific medical conditions**

Some medical conditions are found more commonly in PWLD, e.g. problems with continence, and some are associated with specific conditions (*see* 'Physical impairments: aetiological and pathological groups' and 'Syndromes of impairments and/or disabilities' above).

### *Cardiovascular disease (CVD)*

PWLD have high levels of some CVD risk factors. Obesity is more common than in the general population; 19% and 35% of learning disabled men and women, respectively, are obese compared to 6% and 8% of the general population.<sup>90</sup> PWLD are also more likely to lead sedentary lifestyles.<sup>91</sup> There is, however, no evidence for higher levels of hypertension.

Congenital heart disease and its sequelae are common in some groups of PWLD.

### *Infections*

Hepatitis B is reported to have increased prevalence in institutions for PWLD.<sup>92</sup>

### *Dental health*

PWLD often have poor dental health and oral hygiene. Surveys of both children and adults show more extractions, less restorative care and high levels of treatment needed.<sup>93,94</sup> This may reflect low uptake of services and/or specific factors that may increase the need for intervention, such as dento-facial abnormalities, gastro-oesophageal reflux or the effects of regular medication.

## **Restriction of participation: social consequences**

### *Choice*

PWLD often have limited capacity to exercise choice and control over many areas of their lives. This includes where to live, with whom, and how to occupy their time. It also applies to choices about service provision. Studies of young adults with learning disabilities suggest significant lack of choice over future service provision at the transition from children's to adult services.<sup>95,96</sup>

Clearly, the issue of choice is linked to the capacity for consent. Studies suggest that consent and decision making are areas that are poorly understood and addressed by services.<sup>97,98</sup> A person's capacity to consent is a matter for clinical judgement. No one else can consent to or refuse treatment on behalf of another adult who lacks the capacity to consent. The views of carers/families may, of course, be solicited and taken into account.

The Bournemouth Ruling and subsequent House of Lords decision clarified the issue of consent with respect to the use of the 1983 Mental Health Act. This made it clear that compliant, incapacitated patients could continue to be admitted and treated, in their best interests, under section 131 of the Mental Health Act, without the need for them to be formally detained under section 2 or section 3 of that Act.<sup>99</sup>

### *Relationships*

The capacity to create and sustain relationships is fundamental to quality of life for most individuals. For the majority of PWLD in the community and in residential care, relationships outside immediate family/carers are usually with service providers.

It is estimated that there may be 250 000 parents with learning disabilities in the UK.<sup>100</sup> Most will have mild or borderline intellectual impairment and at least 60% will have children who have higher intellectual functioning than them. Many of these parents will need specialist help to acquire parenting skills and to live independently in the community. Without such help their children may be 'at risk' for developmental delay and abuse, probably arising from unintentional neglect. It is difficult to disentangle the role of

learning disabilities in these outcomes, as opposed to the impact of socio-economic factors. The children are likely to be over-represented in childcare services.<sup>101</sup>

PWLD may have limited knowledge/access to information about family planning and safer sex.<sup>102,103</sup>

### *Abuse*

PWLD suffer high levels of sexual, physical and emotional abuse. This applies to those living in their own homes and to those in residential care.<sup>104</sup> It has been estimated that 1400 adults with learning disabilities, both men and women, are reported as victims of sexual abuse in the UK each year. In a significant number of cases, abuse is perpetrated by other PWLD, predominantly a small number of men, who may offend on more than one occasion.<sup>105</sup>

### *Crime*

PWLD are often the victims of minor crimes. The criminal justice system may not be involved, the situation being dealt with by service providers. This also applies in cases of sexual abuse.<sup>105</sup> Despite this, PWLD are often thought of as perpetrators rather than victims.<sup>106</sup>

### *Activities of daily living*

Many individuals with severe learning disabilities will require help with the activities of daily living. Analysis of the OPCS Disability Survey suggested that the majority of adults identified as having learning disabilities and resident in private households needed help with meals/cleaning; 23% were unable to feed or use the toilet themselves and 11% needed help every night (Table 3 outlines the regularity of care needed by those identified in this survey).<sup>89</sup> Similarly, high need for care (based on carers' perception of the need for supervision to remain safe) has been described for individuals on the Leicestershire case register.<sup>26</sup>

**Table 3:** People with learning disabilities in the UK subdivided by age and category of care needs (based on OPCS Disability Survey).

Age group (years)	Care category			
	No care needs (%)	Long-interval self-care needs (%)	No self-care help required, but needs someone present (%)	Short and critical self-care needs (%)
5–15	19	11	15	55
16–34	41	7	23	29
35–49	44	12	26	19
50+	38	21	17	25

These figures are likely to represent people with more severe learning disabilities, as identification in the OPCS Survey was by door-to-door interviews.

Source: Kavanagh and Opit.<sup>89</sup>

## **Restriction of participation: carers and families**

In the 1998 Welsh Health Survey, 7.5% of adults reported that they were carers and one in ten of those cared for had a learning disability.<sup>107</sup> Parents may find it difficult to make the emotional adjustment to

having a learning-disabled child. Adjustment may be influenced by a number of factors, including whether or not they received a false-negative result on prenatal screening.<sup>108,109</sup>

Caring for a person with learning disabilities can place considerable strain on carers and families, having an impact on emotional well-being, financial resources and relationships. The average annual cost of bringing up a child with a severe disability has been estimated at £7355 (at least three times the cost of bringing up a child without a disability).<sup>110</sup> The majority of PWLD and many of their families are poor. Many families are unable to increase their income through paid work because of the demands of caring and/or the lack of suitable childcare.

Carers of adults with learning disabilities report 40% more health-limiting problems than the general population.<sup>26</sup> This is of particular importance as the number of elderly carers increases. A significant minority of PWLD who live in the family home have carers over the age of 70.

## Conclusions

Some degree of intellectual impairment is relatively common in the general population. A minority of these individuals have severe intellectual impairment. There has been a steady increase in the prevalence of severe learning disabilities over the past 20 years. This is likely to continue into the next decade. The number who have multiple and complex disabilities will also increase. These trends need to be taken into consideration in service planning.

Service need is not, however, determined by level of intellectual functioning, although those with the most severe impairment will require services. An individual's need for services is often determined by co-existing conditions, such as those described in the partial categories (*see* 'Partial categories' in Section 3), and by the extent of their social support networks.

## 5 Services available

### Introduction

A range of health, social and educational services is available, comprising both generic services, such as primary care, and specialist learning disabilities services. Services are provided by the statutory and, increasingly, the voluntary and private sectors. The types of services and service providers vary greatly across the country. A key issue in the provision of services is their accessibility. This covers a range of issues: physical access, information in appropriate formats (e.g. Braille), transport provision, the knowledge and attitudes of staff and the provision of training and support to generic staff, users and their carers.

Routine statistics are readily available for only a small proportion of relevant services; notable exclusions are the provision of education, employment and recreational services. In this section, routine statistics are included where they are available. Information on other types of service, such as respite care, is taken from the research literature. Some of the limitations of service provision are discussed in this section. Further information is found in Section 6 on effectiveness of services.

Health promotion, primary care and specialist learning disability services are described in the first part of this section. This is followed by a description of more specialised services for specific conditions, or that address specific needs, such as those described in the partial categories.

## Health promotion

A number of population measures aimed at reducing the incidence or severity of specific conditions may also have an impact on the prevalence of intellectual impairment in the general population (primary and secondary prevention). These include immunisation, genetic counselling, general obstetric services and associated screening programmes (*see* Section 6 for further discussion of this).

### *Health promotion for people with learning disabilities*

*The Health of the Nation: a Strategy for People with Learning Disability* outlines health promotion for PWLD.<sup>111</sup> It emphasises that they should be treated in the same way as the rest of the population and that health gain can be achieved by promoting health surveillance, health promotion and health care. This requires the co-ordinated activity of primary care services, including dentistry, continence, chiropody, etc., and secondary health care, both generic services and specialist learning disabilities services.

### Screening programmes

- **Cervical and breast cancer:** Cervical and breast screening both have low levels of uptake in PWLD.<sup>112</sup> Theoretically, women with learning disabilities have a low risk of cervical cancer as they have low levels of sexual activity. High levels of sexual abuse may, however, have an impact. Some studies suggest low levels of breast cancer, despite the low birth rate in this group.
- **Hypertension:** PWLD have increased risk of cardiovascular disease and therefore blood pressure monitoring should form part of regular health checks, as should advice about diet and healthy living to help combat obesity.
- **Mental ill-health:** Routine screening does not occur. The low levels of detection and diagnosis suggest that increased awareness is needed amongst families, carers and professionals. The screening tool (PAS-ADD Checklist) may help to raise awareness and improve diagnosis.<sup>113</sup>
- **Thyroid function:** Screening is important given the high incidence of hypothyroidism in those with Down's syndrome.

### Immunisation

Influenza, hepatitis B and tetanus vaccinations are important.

## Primary care

Primary care services are central to the organisation of adequate health surveillance for PWLD, who have ordinary needs for primary care and special needs relating to their increased rates of certain conditions. Primary care will also need to provide for the needs of families/carers of PWLD.

### *General practice*

The average practice list of 2000 might expect to have 40 patients with learning disabilities, including children, and approximately eight with severe learning disabilities.<sup>8</sup> In practices which provide services to community residential homes these figures are likely to be higher.



People with learning disabilities have greater physical and mental health needs than the general population (*see* Section 4).<sup>114–116</sup> Problems may only be identified if a screening tool is used, since they may have been missed by professionals, the patient and their carers. The reasons for this include learning disabilities masking symptoms, misinterpretation of symptoms and signs, communication difficulties, and negative or ill-informed attitudes of health care staff. In one survey, many GPs accepted that they were responsible for providing medical care for PWLD, and a third had positive views on health promotion. The majority, however, did not support organised health promotion for PWLD.<sup>117</sup> This could reflect uncertainty about how to meet needs once identified or worries about a perceived unremunerated increase in workload.<sup>118</sup> Estimates of the workload associated with caring for PWLD in primary care vary. Some studies suggest that there is no difference in consultation rates in comparison to control groups.<sup>119,120</sup> Consultation rates may be higher amongst those resettled from institutional care. A rate of eight consultations per year was found in one study, twice the average national rate for 16–44-year-olds and also higher than that for the over-74 group, who average seven consultations per year.<sup>121</sup> The consultation rate, however, says nothing about the assessment/interventions provided, an area much less researched.

### *Chiropody, continence, dietetics, pharmacy and dentistry services*

People with learning disabilities need these services more frequently than those in the general population. Training and support to generic practitioners are required in order that services are easily accessible. In some areas, specialist approaches, such as mobile and domiciliary services, have developed. There are tensions between the development of specialist services for PWLD and encouraging/supporting access to generic services.

Community dental services are the primary provider for those with severe learning disabilities and some adults with mild disabilities, and have an active part to play in oral health promotion.

## **Specialist learning disability services**

Most individuals with uncomplicated mild and borderline intellectual impairment will be able to live relatively independent lives without specific service provision. They may never come into contact with specialist health services, although many will have contact with educational services for assessments of educational need. The following service descriptions are consequently more relevant to the severely disabled group, most of whom will be in contact with services at some point. It is important to remember, however, that although the majority of people with mild or borderline impairment do not require specialist services, those that do include people with offending and challenging behaviours and other conditions such as mental illness. Many of these individuals may not be formally catered for by either specialist learning disability services or general mental health services (*see* ‘Mental disorders’ below).<sup>122</sup> Specialist learning disabilities services also have a role in helping those without additional problems to access generic services and primary care.

Recorded activity in learning disability services has increased in recent years. In England between 1987–88 and 1997–98 there was an increase in first attendances to consultant outpatients from 4000 to 6000. Subsequent attendance also increased. First contacts with community learning disability nurses increased by 40% between 1993 and 1998.<sup>123</sup>

### *Specialist services for children with learning disabilities*

The organisation of services for children and adolescents with learning disabilities differs across the UK. Services may be provided by specialist learning disabilities teams, child and adolescent mental health

services, local paediatric services or child development centres. In many areas, local authority multi-disciplinary disabilities teams provide the point of access to other services and provide community support. A survey of NHS trusts with responsibilities for PWLD found that 72% had services for children, including community services, respite and treatment beds.<sup>124</sup>

Services cover varying age ranges. In a few areas, there are specialist transition teams or social workers to ensure that continuity of care occurs at the vulnerable time of transfer from children's to adult services. The provision of health services that support transition for disabled people with complex health and support needs has been described as 'very patchy'.<sup>125</sup>

### *Specialist services for adults with learning disabilities*

Community learning disability teams (CLDTs) have become one of the most common means of co-ordinating specialist community services for adults with learning disabilities. Most CLDTs in the UK will see people with an IQ of up to 70. Their distribution across the UK is not uniform.<sup>126</sup> Teams provide assessment, treatment interventions and continuing care, and organise support for carers and families. Their role has shifted since the introduction of care management and the transfer of services to the independent sector. This has led to a modest shift from providing specialist services to providing specialist help in accessing ordinary opportunities for housing, leisure and employment, including service brokerage and direct payments.

The breadth of services provided by CLDTs is variable. In some parts of the country they cater for all PWLD, including those with mental health and behavioural problems, whilst in other areas there is specialist provision for these groups.

It is difficult to describe an average team. A survey in London found a fivefold variation in the size of teams from 2.2–10.5 WTEs/100 000. Teams are usually multi-disciplinary, although the composition may vary considerably. Nursing, psychiatry, psychology, speech and language therapy were nearly always part of the team.<sup>127</sup> There is some evidence, however, that teams are increasingly not multi-agency in their organisation.<sup>128</sup>

Teams may include the following disciplines:

- **community nurses/careworkers:** their roles vary depending on the nature of the rest of the team and their background skills and training
- **social workers:** they are organised in different ways depending on the local authority; the role they play also varies
- **consultant psychiatrist:** their role includes assessment, diagnosis and treatment of coexisting conditions, as well as management of aspects of the underlying learning disabilities
- **psychologist(s):** they can provide assessment, functional analysis, a range of psychotherapeutic interventions and consultation/liaison work with other teams/organisations
- **occupational therapist(s):** they work with clients in a number of domains, including work-related activity, activities of daily living, functional assessment, house adaptation and creative therapy. There has been a shift from hospital-based practice to increasing work in the community, and OTs work largely in people's homes rather than in day services
- **speech and language therapist(s):** early intervention is the usual aim. This is more likely to be achieved in disorders that tend to be identified early, such as Down's syndrome. Functional communication is also important, i.e. increasing the range of uses for communication skills, e.g. to express choice
- **physiotherapist(s):** they provide direct interventions using specific therapeutic modalities. These can help to fulfil mobility potential. They may also help to train care and support workers
- **creative therapist(s):** they include art, music and drama therapists.

The organisation of the latter five professional groups is often variable. They might be an integral part of the CLDT, be attached to learning disability services without having a geographical focus, or be part of generic uni-disciplinary teams.

### *Specialist services for older people with learning disabilities*

The organisation of services for people over 65 with learning disabilities varies considerably across the country. The results of small-scale interviews in some parts of the country suggested that there was confusion over responsibility for older people with learning disabilities.<sup>129</sup>

### *Inpatient provision*

Inpatient beds are needed for a small number of PWLD to provide assessment and in some cases treatment for those with the most severe disabilities, physical, sensory or psychological problems. Inpatient facilities are usually provided within specialist learning disability services, but in some areas generic mental health beds are used. Specialist inpatient services for those with mental illness or challenging behaviours are described in 'Mental disorders' and 'Challenging and offending behaviours' below.

### *Other specialist services*

In some areas there is specialist provision for other aspects of care, e.g. palliative care.

## **Alternative therapies**

A wide range of alternative therapies exists, including aromatherapy, cranial osteopathy and massage. Some learning disabilities services have organised access to alternative therapies.

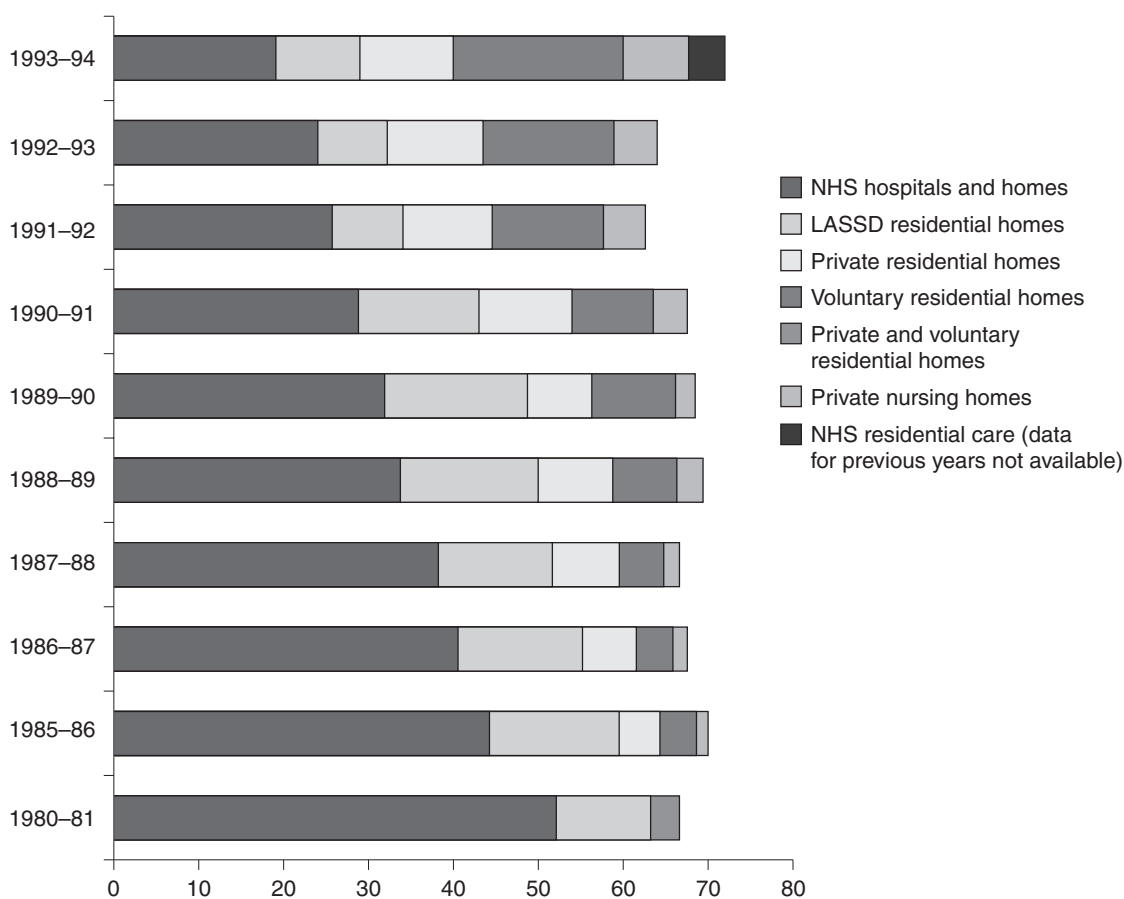
## **Accommodation**

### *Background*

There has been a profound change in the nature of accommodation provided over the past 20 years (*see* Figure 1 overleaf). This is a consequence of:

- the closure of long-stay institutions
- the impact of the NHS and Community Care Act, which encouraged pluralism of care and resulted in shifts from long-stay NHS and local authority residential accommodation into private and voluntary provision
- the acceptance that PWLD should have the opportunity for ordinary life experiences and hence that supported independent living in the community should be the aim wherever possible.

In England, the largest changes in NHS long-stay provision occurred between 1987–88 and 1996–97 when the number of hospital beds for PWLD fell from 31 320 to 7440. Changes in local authority provision were slower (*see* Tables 4 and 5, p. 487), the rate of change differing across the country. In England, local authority residential care places dropped by 10% between 1986 and 1996, more places being provided in



**Figure 1:** Changes in the residential care of people with learning disabilities in the UK, 1980-94.

smaller units. In Wales, over the same period, there was a 50% drop in the number of local authority places, with a significant rise in private-sector provision.

### *Types of accommodation*

Most children and many adults with learning disabilities live with their families.

A wide spectrum of other types of accommodation/homes exists:

- remaining NHS long-stay beds
- nursing home provision
- village communities, catering for up to 300 residents
- staffed and unstaffed group homes
- adult placement schemes
- residential children's homes/schools
- semi-independent living, e.g. supported lodgings
- independent living.

**Table 4:** Residential and hospital provision for adults with learning disabilities in England, 1988–89 to 1998–99.

Type of establishment	1988–89	1998–99
Beds in private nursing homes, hospitals and clinics*	1,260	3,740
Staffed residential homes*†		
Local authority	12,620	7,380
Voluntary	6,530	17,220
Private	7,420	18,010
Places in small (< 4 beds) registered homes*		
Voluntary	(1994–95) 890	8,840
Private	(1994–95) 3,870	
Places in local authority unstaffed group homes*	2840	(1996–97) 2,990
Hospital beds – average daily available		
Short-stay	1,210	1,420
Long-stay	28,400	5,280
Secure	(1994–95) 330	420
NHS residential facilities‡ average daily available beds	(1996–97) 3,430	4,040

\* Data relate to 31 March.

† Excludes nursing care places in dual registered homes.

‡ NHS residential facilities were recorded for the first time in 1996–97. Some of these beds may previously have been recorded under other headings.

Source: Government Statistical Service.

**Table 5:** Residential and hospital provision for children with learning disabilities in England and Wales, 1987–88 to 1997–98.

Type of establishment	1987–88		1997–98	
	England	Wales	England	Wales
Beds in private nursing homes, hospitals and clinics*	130	9	70	–
Places in staffed residential homes*†				
Local authority	2,120	60	1,070	66
Voluntary	370	61	290	145
Private	170		350	
NHS hospital beds – average daily available				
Short-stay	200	26	280	0
Long-stay	510		100	

\* Data relate to 31 March.

† Excludes nursing care places in dual registered homes.

Source: Government Statistical Office and Welsh Office direct communication.

There is significant variation in the type, quality and quantity of residential accommodation across the country. Analysis of the 1991 Census showed that, in England, the number of residential places/100 000 general population varied from 9.2 in the old North East Thames Regional Health Authority to 18 in the South Western Region.<sup>130</sup> In Scotland, the average figure was 11.9, compared with 10.4 and 12.4 for Wales and England, respectively. This analysis excluded people living in their own homes, adult placement schemes and supported lodgings. These provide a relatively small proportion of all accommodation and

their exclusion is unlikely to explain the differences reported. The fact that only designated places for PWLD were included may have had some effect.

Over the past 10 years there has been an increasing emphasis on providing supported living in the community (creating the opportunity for PWLD to live in their own homes through the provision of flexible, individualised support). The actual increase in supported living arrangements has, however, been slow. A survey of 10 local authorities in 1996 showed that 5% of adults with learning disabilities were in adult placement schemes and only 8% were in their own homes/tenancies.<sup>131</sup> Similar results were found in a more recent study.<sup>132</sup> In London in 1999, however, it was found that 27% of accommodation provided was some form of supported living.<sup>127</sup>

Planning for future provision will need to take into account decreasing NHS places, the increasing average age of carers and improving survival to old age, particularly amongst those with complex needs.<sup>133,134</sup>

## Daytime activity

The capacity to engage in meaningful activity during the day is a key measure of quality of life. Activities may include paid work, education, day care, training and leisure activities, and should be dictated by the needs and desires of the individual. The majority of organised daytime activities are provided by day-care facilities.

### Day care

There is up to 10-fold variation in the number of standardised day-care places across local authorities. Approximately 50% of all local authority day-care places are for PWLD, and 60% of all local authority-purchased places for the under-65s are for this group. Table 6 shows the purchasing of local authority and NHS day-care places. Equally variable is the nature of day-care programmes provided. They may include centre-based activities, adult education, training or community leisure activities.

**Table 6:** Day-care places for adults with learning disabilities in England, 1992–93 to 1996–97.

Purchaser/provider	1992–93	1996–97
Local authority		
Local authority	233,000	268,900
Voluntary	3,000	11,300
Private	200	6,700
NHS		
Total attendances	970,205	1,291,980
First attendances	4,145	8,980
On register 31 March 1999	8,469	

Sources: Government Statistical Service. *NHS Day Care Facilities England 1998/9*. London: Department of Health, 1999.

Government Statistical Service. *Community Care Statistics. Day and domiciliary personal social services for adults. Detailed statistics for England*. London: Department of Health, 1998.

Day care for PWLD may be provided by a variety of facilities.<sup>135</sup> Over the past decade there has been considerable change in the way in which day-care services are provided. The trend has been to move from the large segregated centres to supporting people in more ordinary everyday settings.<sup>136</sup> Key principles in this shift are integrated provision, person-centred planning and community inclusion. Despite this trend, the majority of local authority spend for day care is on day-centre places that tend to focus on large group activities.

Broad descriptions of models are listed below, although the model and way of working may not be fixed.

- **Adult training centres:** These were typically built for 100–120 people and are often located in light industrial estates. They are usually based on an industrial/work-training model. Special units for 10–20 people with special needs may be attached. Typical staffing ratios are 1:7–1:10 in training centres and 1:3–1:4 in special needs centres. In 1991 there were 662 local authority training centres and associated special care units in England.
- **Large day centres:** These accommodate up to 50–100 people. The centres were originally developed with a more educational focus than adult training centres.
- **Small day centres:** The limitations of large facilities led to smaller developments, typically for around 50 people, with staffing ratios of 1:5–1:7.
- **Community day centres:** These are typically built to accommodate up to 20 people. The growth of these centres has been encouraged by the increasing emphasis on community-based care and life skills training, alongside community integration. Staff ratios are typically 1:3–1:4, with an emphasis on 1:1 activity.
- **Day hospitals:** A small number of PWLD attend health care assessment and treatment units on a daily basis.

### *Employment*

PWLD may be in ordinary employment or a variety of sheltered or supported work schemes. Over the past decade the trend has been to provide placements in supported work environments, with significant growth in supported employment schemes. The basic principles of supported employment are integrated settings, real work for real wages, ongoing support and training in the workplace. The term ‘supported employment’ is, however, sometimes used more generically to refer to all assisted employment.

The number of supported employment schemes for people with disabilities, including those with learning disabilities, has increased significantly since the early 1980s, although there has been some evidence of a slowing in growth.<sup>137,138</sup> In 1992, there were 1600 people in supported employment in the UK, with 79 agencies providing support. By 1995 this had increased to 200 agencies supporting 5000 individuals; the largest group were people with learning disabilities.<sup>138</sup>

Studies suggest that though many people in schemes earn less than £50/week, benefit cuts become an issue on higher incomes. Some people, particularly those with severe learning disabilities, are not paid at all. The majority of people work part-time.<sup>139,140</sup>

The provision of supported employment is unevenly distributed. There are relatively more schemes in Wales, the North West, the South East and London than in other parts of the country. Demand for placements always seems to outstrip supply. It has been estimated, for supported employment places in general, that at best there are only half the number of places needed and at worst up to 180 000 people are in need, with only 22 000 places.<sup>141</sup>

Schemes are usually funded through health and social services, some with contributions from the Department of Education and Employment. They are run by various agencies, including the voluntary sector and local authorities.

## Education

The emergence of education as a key service for both children and, increasingly, adults with learning disabilities has been a marked feature of provision since the 1981 Education Act. The Special Educational Needs and Disabilities Rights in Education Bill 2000 clarifies the responsibilities set out in the 1996 Education Act for pupils with special educational needs.

## Children

- **Pre-school provision:** A number of different schemes are available. Portage is probably the most commonly available for children with all types of special needs. This approach is designed to improve or ameliorate developmental delay. Portage teachers visit parents and their children at home. They work with parents to help develop skills and achieve specific targets. In 1992, there were 300 schemes in the UK.

All local authorities must establish Early Years Development and Child Care Partnerships. Their annual plan should include provision for all young children, including those with disabilities and special educational needs. From 2001, all early years provision has been covered either by part 11 of the Disability Discrimination Act or by the Special Educational Needs and Disabilities Rights in Education Act. All early-years providers will be expected to make reasonable adjustments to increase access and inclusion for disabled children. Sure Start sites should also play a part in early identification of children with disabilities.

- **Schools:** The 1996 Education Act and Code of Practice sets out the framework for assessment and provision for children with special educational needs.<sup>142</sup> For those children with complex needs, including those with learning disabilities, the assessment process draws advice from the child's school, local education authority (LEA) and health and social services to determine the child's needs and how best to meet them. If this process concludes that the pupil needs provision over and above that which the local school could be reasonably expected to provide, then a statement of special educational needs will be made. This will specify the provision and set targets that will be reviewed annually.

At the 14-plus review the LEA should create a transition plan. The Learning and Skills Act introduces a Connexions service which will provide a personal adviser from age 14 onwards. In the case of those with learning disabilities this service will continue until age 25.

Estimates, although not precise, suggest that up to 28% of the school population may have special educational needs at some point during their childhood; only 2–4% will receive statements.<sup>143</sup>

There is growing inclusion of children with disabilities, including those with learning disabilities, into mainstream education. There is, however, significant variation between LEAs in the rate at which this is being achieved. Children with learning disabilities are consequently educated in a variety of settings – specialist provision in boarding and day special schools, in special units attached to ordinary schools, and supported in mainstream classrooms. Clearly the level of disability will greatly dictate their placement, as will local provision. The proportion of children educated in special schools varies from 0.5–2%, depending on the LEA. Nationally, the special school population covers about 1% of the total school population (approximately 98 000 children).<sup>143</sup>

## Adults

- **Further education:** The Learning and Skills Act 2000 replaces the Further and Higher Education Act and in effect gives new rights in education for all disabled people. The Further Education Funding Council has been replaced by the Learning and Skills Council with local Learning and Skills Councils



being responsible for managing further education and training in their area. A person with learning disabilities will be entitled to ongoing assessment and review up to age 25.

The provision of further education seems to have increased for people with moderate learning disabilities. In one survey, 60% of colleges reported increased numbers since Further Education Funding Councils were given the responsibility for 'having regard for' the needs of PWLD. However, one in ten institutions had faced cuts, particularly for those with severe or profound disabilities. It was also found that the elderly might be marginalised.<sup>144</sup>

- **Adult education:** Provision of adult education is an important part of many day-care programmes, although the extent of provision is variable.

### *Leisure*

Leisure activities may be organised by local authorities as part of day-centre programmes or as part of borough Gateway Clubs. Some projects are specifically for those with disabilities, whilst others aim to support people in accessing everyday activities, such as becoming members of local sports clubs. Self-advocacy groups also organise social and leisure activities.

Local authorities vary as to whether they provide grants for holidays.

## **Syndromes of impairment and/or disabilities**

Mental disorders are dealt with separately under 'Mental disorders' and 'Challenging and offending behaviours' below.

### *Epilepsy services*

A significant proportion of people with epilepsy who are in touch with specialist epilepsy services have learning disabilities.<sup>145</sup> Epilepsy management is often provided by consultants in learning disability, many of whom have developed specific expertise. In other areas, neurologists and paediatricians provide a service. Few neurologists have a special interest in epilepsy.<sup>146</sup> GPs have little specialist knowledge of epilepsy management and tend to rely on specialist services. An integrated approach to management should cover neurological, psychological and social care. There are national specialist centres for the treatment of refractory epilepsy.

## **Mental disorders**

There is a perceived gap in many services in the provision of mental health services for PWLD. This is particularly true for individuals with mild or borderline impairment, for children and for the elderly.<sup>147</sup>

### *Services for children with learning disabilities and mental ill-health*

It has been estimated that up to 50% of children with a learning disability are likely to need special services for emotional/mental health problems at some time during their childhood.<sup>148</sup> The provision of local services is highly variable. It may be any combination of paediatric, child development, specialist learning disability and child and adolescent mental health services.

### *Services for adults with learning disabilities and mental ill-health*

Most services for adults with learning disabilities and mental illness are associated with specialist learning disability services, with specialist learning disability mental health teams in some areas. These teams usually provide interventions over the short to medium term. Few learning disability mental health services are part of generic mental health services. Occasionally a specialist learning disability team is integrated into generic services. In many areas, the specialist learning disability team also covers challenging behaviours.

There is some evidence to suggest that, in recent years, there has been a rise in demand for mental illness learning disability services. This may reflect changing criteria applied by social services to providing care for PWLD or increased detection of learning disabilities and mental illness by the criminal justice system and generic mental health services.

In most parts of the country there are specialist wards or community units, with a small number of areas relying on generic mental health service provision for inpatient care. There are relatively few joint inpatient schemes, where adult mental health beds are supported by learning disabilities teams.<sup>149</sup> Local service history and geography often dictate the model found. If there is no local service, inappropriately distant placements may occur.

Specialist day services are provided in some areas.

## **Challenging and offending behaviours**

Challenging behaviours, especially aggression and self-injury, are amongst the most common reasons for referrals to psychiatrists and psychologists. A variety of specialist services exists, including outpatients, day care, supported accommodation, and open and secure inpatient units. In some areas, specialist challenging behaviours teams have been established.

The provision of secure services has changed significantly in recent years. The three high-secure hospitals provide beds for a small number of individuals, and high-secure learning disability services are now centred at Rampton Hospital. Admissions have decreased, acknowledging the inappropriateness of this setting for all but a few PWLD. Alternative services have developed, including a rise in the number of medium-secure beds. The number of places available in England increased from 300 in 1992–93 to 420 in 1998–99. Despite this increase there is still a perception that there is under-provision of the lower levels of secure care.

## **Autistic spectrum disorders**

A wide range of provision is required to meet the diversity of need displayed by both children and adults with ASD.

### *Children with ASD*

- **Education:** Children with ASD may attend mainstream education (with or without specialist support), generic special schools or designated units for ASD, or receive home-based tuition. It is often the level of intellectual impairment that dictates the type of placement. As IQ diminishes, specialist placement is more likely. There are, however, some children within the spectrum with good intellectual skills, whose needs may best be met by specialist provision if, for example, they find it too hard to cope with the social pressure of peers in mainstream education.

In 1997, there were 12 schools in England and one in Scotland solely for children with ASD, run by either the National Autistic Society ( $n=5$ ) or local education authorities ( $n=7$ ). There was one independent school for children with Asperger's syndrome, although most will be in mainstream education. A small number of independent schools offer places for ASD. There is enormous variation between LEAs as to the nature of local provision, and most schools use a variety of approaches to educational support.<sup>150</sup>

- **Speech and language therapists:** These professionals are often involved with services, as language delay and communication difficulties are key concerns for parents, and are predictors of prognosis.

### *Adults with ASD*

Individuals with ASD require highly structured environments. Services should be organised to provide the familiarity and predictability needed. It is often the case that neither adult psychiatric services nor specialist learning disabilities services are set up to provide adequately for those with Asperger's syndrome.

Most PWLD and ASD will eventually need some form of residential care. Much of this is provided by the voluntary and independent sector.

## **Specific restriction of activities: losses of function**

### *Sensory impairment*

In some parts of the UK specialist provision exists, including hospital-based accommodation and specialist-staffed housing with structured programmes.

Audiology and ophthalmology services with interest and expertise in screening and the fitting of aids for PWLD are needed, given the high levels of unrecognised morbidity.

### *Multiple disabilities*

- **Children with multiple disabilities:** The majority of children with complex and multiple disabilities are cared for by specialist teams, which include paediatricians, physiotherapists, speech and language therapists, occupational therapists and specialist nursing staff.

Increasingly, packages of care allow treatment and care in a home setting, although regular respite care is needed. It may be necessary to provide this in a hospital setting for the most severely affected.

Transition to adulthood is a vulnerable time, especially as some of the co-ordination of care may be lost with the shift to adult services.<sup>97</sup>

- **Adults with multiple disabilities:** Many people with the most complex disabilities are, since the closure of long-stay institutions, cared for in home environments or in residential/nursing homes. Only a few of the most disabled are looked after in hospitals. In some areas, high levels of community-based health care have been organised to allow individuals to live in ordinary home settings. This requires good collaboration between physical rehabilitation, learning disability and paramedical staff.

## **Restriction of participation: social consequences**

PWLD often require help to access and understand services and to take an active part in the way in which their care is organised. Advocacy services, interpreters and training front-line staff to understand and deal with PWLD will help to achieve this.

### *Advocacy*

There are a variety of approaches to advocacy, from the involvement of health and social care professionals in helping their clients to access services, to specific services for self- and citizen advocacy. Advocacy may provide a range of functions, including befriending, advice and direct representation.

There was a significant rise in advocacy services during the 1980s, particularly in self-advocacy groups. Nationally, between 1980 and 1987, there was an increase from 87 to 231 self-advocacy groups.<sup>151</sup> In Wales there was an increase from two groups in 1985 to 58 groups in 1995.<sup>152</sup>

### *Relationships*

- **Parenting programmes:** Most parenting programmes in the UK are aimed at the general population, with no specific provision for parents with special needs. There are some specific services for parents with learning disabilities, such as the special parenting service in Cornwall.<sup>153</sup>

## **Restriction in participation: carers and families**

Families and carers require information, advice, training and support from a range of services. Respite care is a key component in providing carer support.

### *Respite care*

Respite care provides a break for carers, particularly if the client has multiple problems, severe challenging behaviours, or terminal or severe physical illness, and it covers carer illness or other emergencies. Most local authorities have some respite facility, but there is considerable variability in its availability.

Respite care may be provided in a variety of settings, including hospital wards, residential or nursing homes, specialist services such as outdoor-pursuit centres, and family settings. The current emphasis is on providing short respite breaks within a family setting rather than within residential units. This has been implemented to a varying degree across the UK.

- **Family-based respite:** At the end of the 1990s there were at least 400 family-based respite schemes in operation across England, Wales and Northern Ireland,<sup>154</sup> an increase of 26% in children's schemes and 4% in adult schemes since the previous survey at the beginning of the 1990s.<sup>155</sup> The majority of these services made provision for learning disabilities, and 85% of children's and nearly half of adult schemes accepted users with physical disabilities. The majority of schemes accepted people with sensory impairments. A significant proportion of the users had behaviour that was considered challenging. This finding is important, as the previous survey had found that there were difficulties in finding placements for those with physical dependency or challenging behaviours.<sup>156</sup>

There has been some diversification in the types of services provided. Many schemes provide sitting services and others provide befriending or escorts to holiday placements.

Adult and children's schemes usually had significant waiting lists, owing to a shortage of carers and/or funding. A third of users waited over a year for the service. Schemes are funded from a variety of sources, the majority from social services budgets.

## **The cost of services**

The costing of services for PWLD is complex. In 1996, total hospital and community health service expenditure on 'learning disabilities' was £1376 million (or 5% of the total for England). Personal social

services expenditure for 'learning disabilities' was £1080 million (13% of the total).<sup>157</sup> These estimates exclude significant service utilisation, as data are not easily separated for particular diagnostic or client groups. Kavanagh and Opit's more comprehensive cost estimate (using the same baseline figures) includes social services, primary care and education, and suggests an annual figure in excess of £3 billion for the UK.<sup>89</sup> Funding mechanisms have diversified, as the balance of care has altered over time. Direct payment for services is now also an option for PWLD, although it is still relatively little used (*see* 'Choice' in Section 6).

Some commentators suggest that significant further investment is needed. The Mental Health Foundation estimated that a further £53 million was needed up to year 2001.<sup>158</sup>

### *Resource allocation*

The original York formula used to allocate funds to health authorities (now PCTs) contained no weighting for learning disability services. It has been argued that this is inappropriate, as socio-economic indicators may predict need, not because they necessarily predict prevalence, but because need for services may be greater for those on low income.<sup>159</sup>

### *Health benefit groups (HBGs)*

The development of HBGs for community care services presents considerable difficulties. This is particularly true for PWLD, as the main need is often for social rather than health care. Initial work on iso-resource groups suggests that approximately 30–40% of variation in costs can be accounted for using a bi-axial model that includes severity of intellectual impairment and presence or absence of severe challenging behaviours. This classification only accounts for a negligible reduction in variations in costs if NHS costs are considered in isolation (this may reflect either case-mix issues or methodological problems).<sup>160</sup> Further work on cost data is being undertaken.

### *Service costs*

The Personal Social Services Research Unit (PSSRU) at the University of Kent at Canterbury produces annual costing schema for a variety of services and professional groups, based on the best available evidence. Table 7 (*see* overleaf) outlines the costs for individual practitioners.

The costs for specific aspects of learning disability services are hard to generalise, given that case-mix and service characteristics are so variable. Table 8 (*see* overleaf) shows a summary of the costs of different aspects of care.

## **Conclusions**

Across the UK the organisation of services for PWLD differs significantly in both structure and level of provision. There are gaps in service development across the spectrum of health and social care. It is unlikely that differences in need can explain the pattern of provision that exists. Further investment is likely to be required if these disparities are to be addressed. Similarly, investment will need to take into consideration the potential increase in numbers of individuals with severe learning disabilities, the ageing of the existing population and the needs of carers, particularly as they also age.

**Table 7:** Costs of professional groups working with people with learning disability.

Professional group	Costs in 1997 (£)			
	Wages	On costs	Unit cost/hour	Cost/hour client contact
Occupational therapist – community	18,538	2,167	17	29
Speech and language therapist – community	20,753	2,415	19	31
Physiotherapist	20,753	2,415	19	31
Clinical psychologist	27,863	3,321	25	56
Community psychiatric nurse (G-grade)	20,774	2,417	19	52
Auxiliary nurse – B-grade community	10,300	921	9	15
Social worker	19,556	2,378	17	23/hour client-related work; 83/hour patient contact
Psychiatrist				
Consultant	56,407	7,375	50	68/hour client-related work; 207/hour patient contact
Senior registrar	36,144	4,096		17/hour on duty; 25/hour worked Costs based on average wages in 1997, excluding London weighting

Source: Netten *et al.*<sup>295</sup>

**Table 8:** Average cost per person with learning disability in different care settings (£/week, 1994–95 prices).

Care setting	NHS (£)	LASSD (£)	FHSA (£)	Family/DSS (£)	Education (£)	Total cost (£)
Adult fostering schemes*						658
Adults in sheltered housing*						560
Adults in ordinary households†	13.02	100.79	1.50	140.65	0.00	256
Children in ordinary households‡	21.18	13.18	2.03	114.68	179.51	331

Other: Local authority residential care‡ – £659, £702 for care package including services provided by other agencies and personal living expenses.

Voluntary-sector activity-based respite care‡ – £53 per session per client.

Local authority social education and daycare centres<sup>3</sup> – £39 per place per day.

\* Knapp *et al.*<sup>219</sup>

† Kavanagh and Opit.<sup>89</sup>

‡ Netten *et al.*<sup>295</sup>

## 6 Effectiveness of services

The determination of the effectiveness of services and interventions for PWLD is complex. This is for the reasons listed below.

- Definitional problems (*see* 'Definitions and classification' in Section 2) and the varied case-mix within services. The comparison and generalisation of research findings is thus difficult. In addition, what works in well-controlled research conditions may not work in the average service (the tension between known efficacy and actual effectiveness).
- The complexity of client problems and multi-agency/multi-intervention approaches to their management.
- The potential inappropriateness of extrapolating knowledge about effectiveness from non-learning disabled populations to PWLD.
- The determination of client satisfaction may be hampered by communication difficulties, reliance on the views of third parties and the fact that, historically, PWLD have not been encouraged to state their views.
- Different parties may place different values on the outcome of service provision, e.g. in relation to respite care there may be a trade-off between the benefit to the carer and the potential for dis-benefit to the person with learning disabilities.

### Approaches to the determination of effectiveness

There are a variety of approaches to the determination of desirable outcomes. Overall, effectiveness should be gauged by improvements in the quality of life for individuals. The difficulties in defining quality of life, in addition to the methodological issues outlined, mean that this ideal is often not realised. Evaluation of service quality is more likely to measure the structure and process of provision that is thought to be associated with desirable outcomes, such as:<sup>161</sup>

- inputs, e.g. medication, physical characteristics of the care setting, staffing ratios and training
- processes, e.g. movement between settings and community presence
- technical processes, e.g. care planning
- interpersonal processes, e.g. staff/client interaction or the social environment of a facility.

Despite this, attempts should be made to measure well-being and subjective as well as objective outcomes.

#### *Outcomes for the general population*

The effectiveness of population measures for the prevention of disease, such as immunisation rates and coverage of screening programmes, will have an impact on the incidence and severity of learning disabilities and associated conditions. These interventions are discussed under 'Primary prevention' and 'Secondary prevention' below.

#### *Outcomes for individuals*

In learning disability services, the impact of aspirations to attain an ordinary life have probably had more of an impact than in other community care services. These aspirations are often underpinned by the five accomplishments defined by O'Brien, arising from work on the concept of normalisation.<sup>162</sup>

Normalisation principles are commonly used to define services and individual objectives and can therefore also be used to judge the quality of service provision.<sup>163</sup>

The five accomplishments are listed below.

- **Community presence:** The sharing of ordinary places that define community life.
- **Choice:** The experience of autonomy in small everyday matters and in large life-defining matters.
- **Competence:** The opportunity to perform functional and meaningful activities with whatever level or type of assistance that is required.
- **Respect:** Having a valued place among a network of people and valued roles in community life.
- **Community participation:** The experience of being part of a growing network of personal relationships, including close friends.

Given the vulnerability of many PWLD, safety and the protection from abuse could reasonably be added to these principles.<sup>164</sup>

Goal attainment in person-centred care planning may be used to measure effectiveness. This might include improvements in specific symptomatology/behaviours, improvement in specific skills, extension of social networks, social integration or meaningful occupation, expressed satisfaction (facilitated by staff, client and carer training or by advocates) or improvements in physical environments.<sup>164</sup> These can give outcomes of success at the individual level and, in theory, be aggregated to look at overall service outcomes. There are difficulties, however, in measuring change across the whole range of ability, including health and social care outcomes. Goal attainment scaling has been used in some learning disability services, but methodological and statistical difficulties limit its widespread usage.<sup>165</sup> Alternative approaches include care pathways or variance analysis of the attainment of care plan objectives.

A number of tools to assist the collection and collation of information about individuals have been developed:

- **HoNOS-LD:** a Health of the Nation outcome scale for PWLD<sup>166</sup>
- **CANDID:** the Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities.<sup>167</sup>

### *Outcomes for carers*

The determination of carer satisfaction with service provision is also important, although the potential for conflict between desirable carer and client outcomes must be borne in mind. Outcomes relating to carer well-being should also be considered. This is a relatively poorly researched area.

## **Health promotion**

This section does not discuss the ethics of preventing people from being born without impairment/disability, but rather it describes the programmes that exist which may contribute to it.

Population measures to reduce the incidence of a disorder can be divided into the following categories.

- **Primary prevention:** The prevention of occurrence of new cases of intellectual impairment through the removal of the causal agent(s), e.g. pre-conception genetic counselling (*see* 'Primary prevention' below).
- **Secondary prevention:** The early identification of intellectual impairment and its subsequent prevention, e.g. the identification of affected pregnancies and selective termination (*see* 'Secondary prevention' below).



- **Tertiary prevention:** The prevention of the development of disabilities associated with intellectual impairment, achieved through the provision of effective services for affected individuals (*see* from ‘Primary care’ on p. 500 to and including ‘Restriction of participation: social consequences’ on p. 512).

### *Primary prevention*

The primary prevention activity that relates directly to intellectual impairment is the provision of genetic counselling. Other (indirect) measures aim to prevent pathology associated with learning disabilities, e.g. neural-tube defects or head injuries.

- **Genetic counselling:** High-risk families and individuals can be identified, counselled and offered genetic screening (cascade screening). This can increase choice and thus hopefully maximise quality of life, for example in relation to fragile X. In New South Wales, Australia, active case finding, screening and selective termination have been operating for 10 years. This has resulted in an estimated reduction in the prevalence of fragile X from 0.25/1000 males to 0.1/1000.<sup>168</sup> UK genetic testing centres offer testing to relatives of affected individuals, but case finding is not systematic. Further research is likely to be needed before active screening programmes could be implemented in the NHS.
- **Antenatal care:** General dietary advice is likely to be helpful in increasing pregnant women’s energy and protein intake, although the maternal, fetal or infant health benefits are not clear.<sup>169</sup> Advice on limiting alcohol intake in pregnancy should also be of benefit.

Randomised trials have shown that neural-tube defects can be reduced if folate supplements are taken before conception and in early pregnancy.<sup>170</sup> The incidence of neural-tube defects has reduced significantly over the past 30 years. Much of this occurred before the 1992 advice that all women trying to conceive should take daily folic acid supplements. This has led to recommendations that food should be fortified to ensure adequate population coverage.<sup>171</sup> General antenatal care measures, such as those aimed at reducing low birth weight, may be effective. Rhesus immunisation of rhesus-negative mothers has significantly reduced the birth of babies affected by rhesus incompatibility, many of whom would otherwise suffer brain damage.

- **Immunisation:** Programmes to reduce rubella, measles, mumps, haemophilus influenzae and whooping cough may all contribute to the reduction of brain damage associated with childhood infections. The routine use of rubella vaccination to increase the general population’s level of immunity may also reduce the incidence of intrauterine infections.
- **Environmental strategies:**
  - **head injuries:** a reduction in the incidence of head injury caused by accidental and non-accidental injury (NAI) will have an effect on the incidence of intellectual impairment. Safety features in playground design and support measures for families with children at risk of NAI will theoretically therefore have an impact
  - **lead:** the Australian Port Pirie Cohort Study suggests an association between blood lead levels and IQ.<sup>172</sup> The impact on IQ is small and its importance is debated. At a population level, however, even small shifts in IQ may be significant. Exposure reduction, e.g. through removal of lead from paint, judicious siting of children’s play areas and the use of unleaded petrol, may therefore be of benefit. There is some evidence to suggest that these measures may have an impact, as blood lead levels across all age groups in the UK are reported to be significantly lower than they were in the 1980s.<sup>173</sup>

### *Secondary prevention*

Secondary prevention relies on screening programmes either to detect affected pregnancies and offer termination, or to identify affected babies and institute early treatment.

- **Antenatal screening:** Antenatal ultrasound screening at 16–18 weeks can detect a variety of major structural anomalies/disorders that are associated with learning disabilities. Antenatal detection of infections such as rubella, syphilis and HIV can also contribute to reductions in affected babies. Cost–benefit analysis has suggested that, even in areas where prevalence of syphilis is low (East Anglia), antenatal screening remains worthwhile.<sup>174</sup> Neural-tube defects can be detected antenatally by measuring maternal blood alpha-fetoprotein levels (routine antenatal practice in England and Wales). Some defects are detected at routine ultrasound scanning.

The screening of pregnancies to detect a high risk of Down's syndrome is routine practice in England and Wales. Screening tests vary and may include blood tests (assays for two, three or four serum markers – double, triple or quadruple testing), ultrasound screening, including nuchal translucency measurement, and estimates of risk based on maternal age. Estimates suggest that, in 1998, serum screening was offered to about 70% of pregnant women in the UK.<sup>175</sup> Once high risk is identified, chromosome analysis (by amniocentesis or chorionic villous sampling) and selective termination can be offered. Chromosomal testing is also usually offered to women in known high-risk groups, defined by age and by having previously affected children. Current screening policy and practice vary considerably across the country, with some women being screened more than once at different stages of their pregnancy. There is a role for improved staff training and communication of information to patients.<sup>176</sup>

Research evidence indicates that using the triple test with age is more effective, safe and cost-effective than the double test.<sup>177</sup> Depending on the combination of markers used, between 36% and 76% of affected fetuses can be detected in clinical practice.<sup>178</sup> However, the overall cost-effectiveness of the serum screening programme has been questioned, given the possibility of higher than predicted prenatal diagnosis based on maternal age and mid-trimester ultrasound alone.<sup>179</sup> There is continued debate about the relative effectiveness of nuchal translucency vs. serum screening.

The usefulness of screening for cytomegalovirus and toxoplasma is less clear-cut, and it is not routinely used in the UK.

- **Postnatal screening:** The screening of all neonates to detect phenylketonuria and congenital hypothyroidism (Guthrie test at age 10 days) is routine practice in the UK. Early treatment can prevent significant intellectual impairment in both of these disorders. Cost–benefit analysis suggests that screening for PKU alone justifies the continuation of such neonatal screening. There is insufficient evidence to assess the economic value of screening for other inborn errors of metabolism.<sup>180,181</sup>

### **Primary care**

The high levels of unrecognised morbidity and low uptake of health promotion suggest that the current provision of primary care to PWLD is not particularly effective. Primary health care teams have little expertise in the recognition and treatment of the complex physical or mental health problems that are associated with learning disabilities. Good collaboration between specialist and primary health care teams is therefore essential. This is particularly true with respect to prescribing and drug monitoring.<sup>11</sup>

A number of models have been developed to try to improve the delivery of primary health care to PWLD.<sup>182</sup> In a randomised, controlled trial, full health screening in general practice increased the amount of morbidity recognised and increased the uptake of tetanus immunisation. There is some evidence to suggest that a primary care facilitator, working with practice nurses and GPs, can increase screening and

the detection of health problems.<sup>183</sup> A community learning disability nurse working with the primary health care team can also have a positive impact on the detection of medical conditions.<sup>182–184</sup>

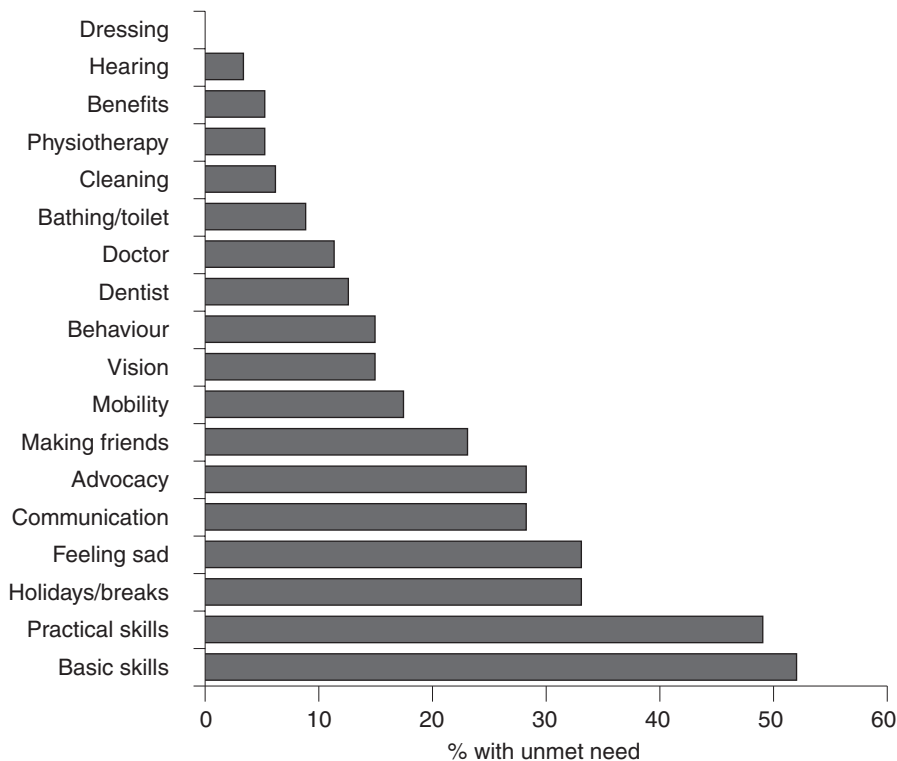
The effectiveness of specific programmes, such as screening for breast and cervical cancer, is not established for women with learning disabilities.

### *Dental services*

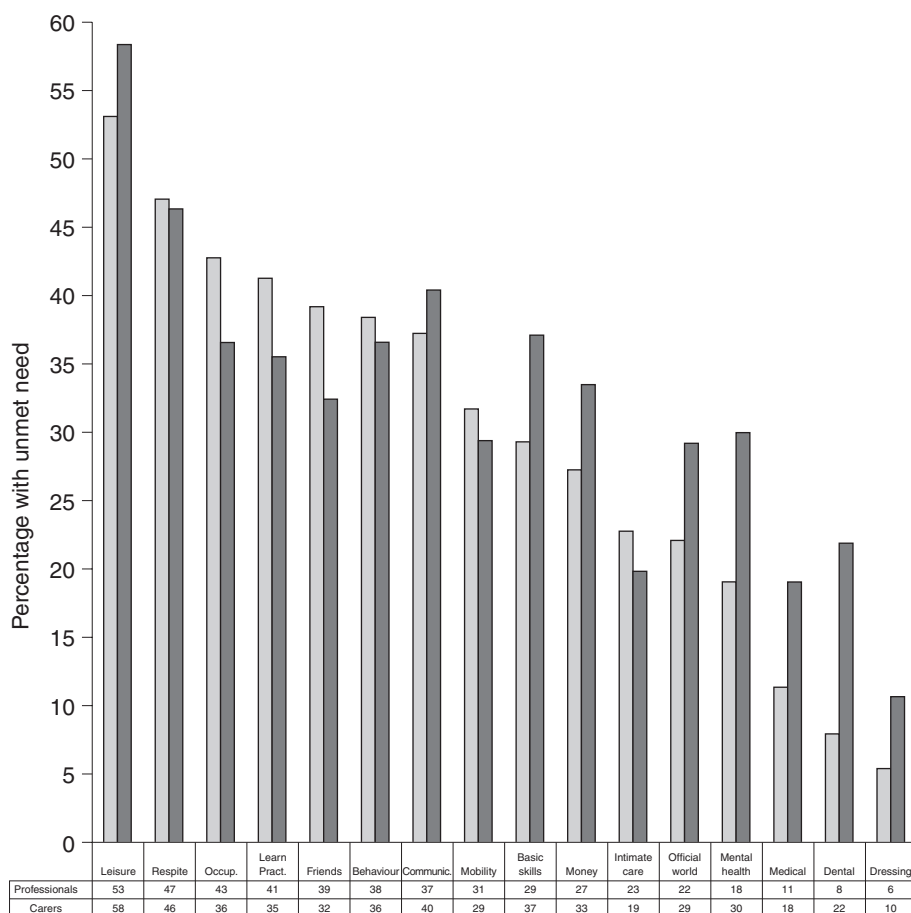
Although not specific to learning disabilities, there is some evidence to suggest that established good practice with respect to oral and dental care is not always put into practice.<sup>185</sup> In some cases, practice may include procedures that are detrimental to good oral health. Good practice guidelines are published by the British Society for Disability and Oral Health.<sup>186</sup>

## **Specialist learning disability services**

As with primary care, an overall measure of the effectiveness of specialist services is the extent to which PWLD have unmet needs for which there are effective interventions. Analysis of the needs of PWLD in the Avon area suggests that many needs are unmet.<sup>187</sup> This was the case whether professionals, carers or clients were asked to assess the extent of unmet need (*see* Figures 2 and 3). Unmet need for daytime activity and respite care was particularly high.



**Figure 2:** Users' perceptions of unmet needs in the Avon area. *Source:* Russell *et al.*<sup>187</sup>



**Figure 3:** Professionals' and carers' rating of unmet needs of users in the Avon area.

Source: Russell *et al.*<sup>187</sup>

Over recent years there has been an increasing movement towards genericism in UK social care, including learning disabilities services. It is unclear what impact this may have on the effectiveness of service provision. For example, the introduction of care management has limited evidence as to its effectiveness.<sup>188</sup> In places where health and social services work well together the standards of learning disabilities services have been judged to be high.<sup>189</sup>

### *Specialist services for children with learning disabilities*

The very varied nature of provision makes it difficult to comment on the overall effectiveness of children's services. General comments on the provision of services to all disabled children and their families were made after SSI inspection visits after the implementation of the Children Act.<sup>190</sup> The SSI reported that:

- within social services departments, services for disabled children were given a relatively low priority
- there was a lack of effective registers of children with disabilities
- the majority of short-term respite was still provided in residential establishments rather than in family settings

- there had been some improvement in consultation procedures with children and an increase in working with parents.

Particular concern has been raised about the effectiveness of transition planning. Highlighted concerns include loss of information, lack of information about services and lack of co-ordination and support.<sup>191</sup> Similar concerns, including lack of collaboration with adult services, were expressed after analysis of local Management Action Plans.<sup>192</sup>

### **Early intervention programmes**

There is a considerable body of evidence for the effectiveness of early intervention, particularly from the USA, but there is relatively little for children identified as having learning disabilities.<sup>193</sup> It is likely that any effective early intervention will be family based, and positive outcomes may be family satisfaction and coping skills rather than lasting impact on cognitive ability of the child. Further research is needed.

### *Specialist services for adults with learning disabilities*

The effectiveness of CLDTs is relatively under-researched, with the exception of specialist provision for challenging behaviours (*see* 'Challenging behaviours' below). Some suggest that CLDTs do, however, provide an example of co-operation between health and social care and have helped link service planning and delivery.<sup>126</sup> It has been suggested that their changing role, particularly with respect to the shift in philosophy around PWLD accessing generic rather than specialist services, has led to 'organisational confusion'. In addition, there may have been a trend towards the underuse of specialist expertise.<sup>128</sup> It is likely that PWLD will benefit most from a mixed approach using both specialist and generic staff.

### *Specialist services for older people with learning disabilities*

There is little specific research. The results of small-scale interviews suggest that there is a lack of opportunity for developing networks with other people of similar ages.<sup>129</sup>

### *Pharmacological interventions*

Only the prescribing of psychotropic drugs is reviewed. These drugs, particularly antipsychotics, are commonly used to treat emotional and behavioural disorders in PWLD.<sup>194</sup> Their use is controversial, in some settings may be widespread, and is often not associated with a formal diagnosis of mental illness.<sup>195,196</sup> The body of research on which to base prescribing policy is relatively poor.<sup>197</sup> Internationally agreed guidelines on the use of psychotropic medication have been published and cover issues such as reducing polypharmacy and close monitoring<sup>197</sup> (*see* also 'Mental disorders' and 'Challenging behaviours' below).

### *Psychological interventions*

There is a significant body of research for some types of psychological therapies, particularly behavioural interventions. There is, however, relatively less published outcome research on cognitive or psychoanalytic therapies. Generally, psychological therapies are not widely used for PWLD, their learning disabilities being used as an exclusion criterion.<sup>198</sup>

- **Behavioural interventions:** There is an extensive published literature, particularly as applied to challenging behaviours (*see* 'Challenging behaviours' below), language and communication difficulties

and the training of caregivers.<sup>199</sup> Research showing the benefits of intervention includes a few small RCTs, many uncontrolled studies and case reports.<sup>200</sup>

- **Cognitive therapy:** Positive results have been reported in the treatment of anxiety, depression and sexual problems and in anger management in people with less severe intellectual impairment. These studies were uncontrolled, with small numbers of subjects.<sup>201</sup>
- **Gentle teaching:** This approach aims to improve the nature of interactions between clients and their carers. There is controversy as to its effectiveness. Research results vary from showing that it has a positive impact to demonstrating that it has a detrimental effect.<sup>202</sup> As an approach, gentle teaching may be a useful adjunct to other more structured approaches.<sup>203</sup>

### *Occupational therapy interventions*

The research base is small. A review by the College of Occupational Therapists suggests that the shift to community working that occurred in the 10 years prior to 1997 led to an increase in direct referrals and a change in their nature. Community referrals are more likely to be for specific interventions to improve skills and independence, rather than for the social and recreational activities.<sup>204</sup>

There is little published evidence for the effectiveness of specific occupational therapy interventions. Small case studies suggest that interventions can have a positive effect on skills and empowerment.<sup>205</sup>

### *Physiotherapy interventions*

The research specific to PWLD is limited. Early intervention is considered important, although there is considerable scope for work with adults in improving functionality, independence and quality of life. Physiotherapists are also increasingly working in the community.

### *Speech and language therapy interventions*

- **Children:** The effectiveness literature is based on small-scale 'before-and-after' research. Overall it suggests that intervention may have an impact on general communication and comprehension.<sup>206,207</sup> An impact on verbal expression has also been shown. Children with learning disabilities were randomised to either a communication training programme or an environmental approach with some structured teaching.<sup>208</sup> The results suggested that the more developmentally delayed children benefited most from the environment approach and the more able ones from the training programme.

The results of research into signing are equivocal, some studies showing no advantage of sign and speech over speech alone.

- **Adults:** There is less evidence for the effectiveness of speech therapy for adults with learning disabilities. There are case studies to suggest that, in well-motivated clients and carers, communication can be improved. It may, however, be more appropriate for group work to be attempted in conjunction with staff training.
- **Carers:** There is some evidence in small-scale studies to suggest that parents' behaviour, in terms of their verbal communication with their children, can be altered. It is unclear what effect this may have on the child.<sup>209</sup>
- **Facilitated communication:** During this process the client is physically supported by a facilitator to help them communicate. There continues to be significant controversy over the usefulness of facilitated communication. There is currently no good evidence to show that it is effective. There is a growing body of evidence to suggest that facilitators may actually influence communication.<sup>210,211</sup>

- **Staff training:** There is some evidence to suggest that health and social services staff may be willing to teach language skills if they have the appropriate training and support.<sup>212</sup> Therefore, given the shortage of speech and language therapists, it may be appropriate for them to act as facilitators and consultants.

## Alternative therapies

Carers and clients value alternative therapies, but there is little evidence to prove or disprove their overall effectiveness or their specific benefits in PWLD.

## Accommodation

The majority of evaluations of services for people with learning disability have focused on evaluating residential care options. Early research compared various ‘community’ placements with long-stay hospital care. It is only recently that the emphasis has shifted to comparing different types of community accommodation.

The available research literature suffers from a number of methodological problems.

- There are no randomised controlled trials.
- Quasi-experimental and descriptive studies have often used poorly matched or unmatched comparison groups and small sample sizes.
- Costing methodologies vary. Not all studies include costs for capital and external services, such as primary care. External costs range from 15–25%. Placement cost estimates are often based on average costs for all residents in a facility, obscuring differences between individuals. Costs are inevitably associated with the level of disability and the presence of coexisting conditions, e.g. challenging behaviours and sensory impairments.<sup>213–216</sup>
- The generalisability of studies is undermined because evaluations are often based on particular schemes or areas where services and other conditions are atypical. Clear differences in the degree and type of disability between different sectors and types of provision have been shown. For example, adults in NHS provision show higher levels of both challenging behaviours and physical disabilities, whilst people in local authority provision are the most able.<sup>217,218</sup>

Despite these difficulties, a number of generalisations may be made concerning hospital and community residential care.

- Community placements have been associated with improved self-reported outcomes for those individuals who were able to express a view.<sup>219</sup> However, on average, resettlement into the community results in little if any improvement in social functioning and symptomatology, and resettlement may actually be associated with small deleterious changes with respect to some behavioural problems.<sup>219</sup> Where small gains in welfare have been reported, they were generally limited to the first few months after resettlement.<sup>220</sup>
- Longer-term research has demonstrated little change in social functioning and symptomatology one and five years after discharge.<sup>221,222</sup>
- Community residential care placements tend to be more costly than hospital care for former long-stay patients.<sup>219,223</sup> Although longer-term costs may alter for particular individuals, there was little change in the average costs of care between one and five years post-discharge.<sup>222</sup>

- A variety of cross-sectional studies also suggest that the costs of community residential placements were higher than for hospital care. The Northern Ireland Care in the Community Study is one of the few studies to show lower community costs over hospital residential care.<sup>224</sup>

The conclusion often drawn from the available literature is that community-based provision is preferable to hospital care, albeit at a higher cost. Debate continues, however, about the appropriate mix of provision in terms of scale, organisation of facilities and the sector of management. For example, an overview of the literature in 1996 found that, on average, smaller-scale dispersed housing schemes were associated with better quality and more positive outcomes for users than larger hostels. It was also noted, however, that significant variations in quality existed within each service type. For a significant minority of people in community residential accommodation schemes, including smaller dispersed housing schemes, quality of care was little better, and perhaps worse, than that experienced in hospital settings.<sup>225</sup> Personal relationships for PWLD in residential care have been reported as being limited in number and quality.<sup>226</sup>

Costs in different accommodation settings vary widely (*see* Table 8). Comparisons of costs are difficult, as residents' characteristics are heterogeneous both within and between different forms of residential care. Costs have been shown to be associated with disability, coexisting conditions and age – older and younger age groups being associated with higher costs.<sup>213</sup> There are also differences in costs between facilities managed by the private, voluntary and public sectors. In general, independent-sector facilities (private and voluntary) are less costly than statutory-sector provision. The lower costs associated with placement in private (for-profit) facilities may, in part, be due to lower utilisation of community services provided externally to the establishment, such as day care.<sup>214,224</sup> Generally speaking, the higher levels of quality reported for smaller staffed group homes compared to larger facilities, such as residential homes or hostels, seem to be achieved at somewhat higher costs.

Advocates for separate village communities for PWLD have suggested that existing community facilities were associated with isolation and an increased risk of misadventure, and incurred higher costs compared with 'village communities' (the definition of a village community appears to include both groups of houses based on a hospital site and clusters of houses in community settings).<sup>227</sup> A number of early studies suggested that clustered community-based accommodation might have lower costs than staffed group homes.<sup>228,223</sup> The extent to which costs were associated with differences in disability between the settings is, however, unclear. A preliminary study by the Department of Health and the PSSRU suggested that the revenue cost estimates which had been suggested were not realisable for people with more severe disabilities, but the results were inconclusive.<sup>229</sup> Consequently, the Department of Health commissioned a large research study.

This suggested that that for residents in community-based village communities the costs of care were £39 796 (1999–2000 prices), compared with costs of £45 532 for a matched sample of people living in dispersed housing schemes.<sup>230</sup> The difference in costs was not statistically significant. Analyses of a range of process measures of quality showed that on some measures the village community provided better quality of care, while on other measures dispersed housing scored better. For example, people in village communities were less likely to have been the victim of crime or verbal abuse, whilst people living in the dispersed housing schemes were more likely to have broader-based social networks. Similarly, people in village communities were more likely to receive preventive health care, while people in dispersed housing were more likely to engage in recreational activities.

The cost of dispersed housing was significantly higher (£57 359) in comparison to residential (NHS) campuses on a variety of hospital and green-field sites (£50 749) (comparisons were again based on two matched samples). Analyses of process measures suggested that dispersed housing provided less institutional and more individually oriented care.

Wide differences in residents' disability existed between the three settings. It was not possible to match a group of people from NHS residential campuses (generally more disabled) with people in



community-based village communities (less disabled). Comparisons of costs adjusted for case-mix suggested that costs were highest in dispersed housing schemes (£52 791), with NHS residential campuses (£45 820) and village communities (£44 030) having broadly similar costs.

### *Supported living*

There is relatively little research on supported living. Some schemes have been established that help PWLD to access and maintain tenancies in mainstream housing, e.g. Keyring in London. Interviews with tenants/key professionals in touch with this scheme suggested that it had been successful in achieving this at a relatively low cost.<sup>231</sup>

### *Hospital-based care*

There are no data on the relative effectiveness of the various models of inpatient care. Evidence (*see above*) seems to suggest that hospital-based bungalows are more costly than more traditional hospital-based care.

### *Accommodation for children with learning disabilities*

There appears to be a gap between current practice and the information available in the research literature. The small research base may, in part, reflect the small amount of full-time residential provision that now exists for children with a learning disability. Most studies were conducted in the 1980s. At that time, the few studies that exist suggested that community care in small-scale units was feasible.<sup>232</sup> Evaluation of an intensive support unit for children suggested that it was an expensive option in comparison to an NHS community unit, once external costs were included, and that foster care was the least costly placement option.<sup>233</sup> Each study was made up of small numbers.

## **Daytime activity**

### *Day care*

The effectiveness of day-centre care is unknown. There seems to be a lack of consensus over its role and purpose, and debate as to whether it does provide a service that creates a meaningful day for people.<sup>234</sup> The people that use day-care centres are not always positive about the activities that they provide, although work and attending college are viewed positively.<sup>235</sup>

### *Employment*

Only a small minority of PWLD are in paid employment (it will not be a realistic option for all). Small-scale interviews with PWLD in supported employment suggest the following:

- they prefer work to traditional day-care options, particularly adult training centres
- having any job is not necessarily preferable to having no job
- they need help to interact with non-disabled colleagues
- it is possible to support severely disabled people in employment.

The costs of supported employment for those with severe disabilities are likely to be higher than ordinary day care, but less for those with lesser disability.<sup>236,138,234</sup> A US review of the cost-effectiveness of schemes

suggested that, overall, supported employment is more cost-efficient than sheltered work placements, although some studies showed advantage for sheltered work for those with severe disability.<sup>237</sup>

### *Leisure*

This again is an area where there is little research on the effectiveness of various models, but carers and PWLD highlight unmet need.<sup>127</sup>

## **Syndromes of impairments and/or disabilities**

### *Epilepsy services*

A significant indicator of the quality of service provision is the level of seizure control achieved. Control may not be total, but can be measured against a baseline. There is some evidence to suggest that good seizure control can have a beneficial effect on activities of daily living.<sup>238</sup>

## **Mental disorders**

The relative effectiveness of different models of service provision for PWLD and mental illness is unknown. Descriptions of the components of services required have been published, but there is no research that compares, for instance, the effectiveness of specialist mental health learning disabilities teams and more generic provision.<sup>239</sup> There is some evidence from a randomised trial to suggest that outreach treatment may be an effective alternative to hospital admission.<sup>240</sup> There is also some evidence to suggest that psychotic patients with borderline intellectual impairment may have better outcomes (less days in hospital and less overall admissions) with intensive case management in the community compared with standard case management.<sup>241</sup> The absence of specialised input may result in distant placements.<sup>242</sup>

There are also no comparisons between mental health units in learning disability hospitals and specialist community units. Similarly, there is no systematic evaluation of learning disability mental illness beds in generic wards with support from specialist learning disability teams. There is some anecdotal evidence that this may be a useful model for those with less severe impairment, but not for severe impairment.<sup>243</sup> A small number of studies have noted that admission facilities are developing a new long-stay population, particularly of people with severe psychiatric or behavioural problems.<sup>244</sup> This emphasises the importance of the development of appropriate community placements.

### *Pharmacological interventions*

Medication may be prescribed for the range of psychiatric disorders, but systematic, specific research for PWLD is limited. A systematic review of relevant randomised controlled trials found no trial evidence to guide the use of antipsychotic medication for those with learning disabilities and schizophrenia. This is an area in need of further research.<sup>245</sup>

## **Challenging behaviours**

As with other service provision, there is some evidence to suggest that many people with challenging behaviours receive relatively little support from services. In 1995, less than 30% of the HARC Challenging

Behaviour Project Group were receiving any contact from community learning disability nursing, psychology, speech therapy, specialist social work or occupational therapy services. This is despite the fact that many were living with their families and had other health and social problems. This study also suggested that there continued to be an under-utilisation of effective behavioural techniques and an over-reliance on psychoactive medication.<sup>73</sup>

### *Services for children with challenging behaviours*

Early intervention is thought to be important, as there is evidence to suggest that children do not 'grow out of' behaviours.<sup>246</sup> A number of controlled intervention trials show positive outcomes for parent training. Some are designed to help deal with general issues, while others address specific problems/challenging behaviours (for a review see Chadwick *et al.*<sup>247</sup>).

Most studies suggest that parental knowledge about behavioural modification can be improved by training. This has been confirmed by videotaping that shows improved teaching expertise. The consequent impact on children's behaviours, however, is less certain. Some studies suggest an improvement in children's self-help skills. The literature is unclear as to whether improved self-help necessarily improves problem behaviours. This is because it is not certain whether the lack of basic skills, such as communication, is necessarily causal in the generation of the challenging behaviours.

Evaluation of interventions is further hampered by relatively low uptake of offers of help and some suggestion that those who accept help may have the capacity for better outcomes, thus biasing the results favourably. It has been suggested that individual rather than group interventions improve the uptake, acceptability and impact on behaviours. Flexibility in the nature of the package offered is likely to be important, particularly with respect to the number of sessions.<sup>247</sup>

### *Services for adults with challenging behaviours*

- **Challenging behaviour teams:** Evidence suggests that staff with specialist skills working with PWLD and challenging behaviours are more effective than teams with more generic skills. The effectiveness of specialist teams is, however, very variable.<sup>248</sup> A number of factors have been suggested to explain this, such as staff training, staff turnover and the extent of teamworking.<sup>249</sup>
- **Day services:** US studies suggest that the availability of day placements is associated with successful community placement for people with challenging behaviours.<sup>250</sup>
- **Psychological interventions:** Small group studies show that the frequency and severity of challenging behaviours can be reduced in the short term using techniques such as functional communication training or behavioural treatments based on functional analysis of behaviours.<sup>251–253</sup> Longer-term effects are less certain; behaviour change is not always maintained by carers/parents after the initial intervention.<sup>254</sup>

Behavioural interventions may not be as widely used as they could be. In one study, less than 40% of people with self-injurious behaviour received appropriate behavioural input.<sup>255</sup> A review of the available guidelines for the psychological management of challenging behaviours suggested that less than 15% were supported by RCT, systematic review or meta-analysis evidence.<sup>256</sup>

- **Pharmacological interventions:** There are case reports for the successful management of behavioural problems with medication, but a lack of long-term trials. Systematic review of randomised controlled trials has provided no evidence as to whether antipsychotic medication does or does not help adults with learning disabilities and challenging behaviours.<sup>257</sup> Furthermore, there is some evidence to suggest that up to 30% of PWLD with behavioural problems, in whom mental illness has been excluded, may have antipsychotics safely discontinued. A further group could be prescribed lower doses without detrimental effect.<sup>258</sup> Drug reduction was associated with a significantly higher

engagement in activities, and weight loss in some. The International Consensus Conference Guidelines highlight the over-prescribing of neuroleptics for behavioural management.<sup>197</sup>

There is some evidence, although the studies have small numbers, that opiate antagonists such as naloxone and naltrexone may improve self-injurious behaviour in a proportion of PWLD.<sup>259</sup>

- **Control of aggression:** There is no robust research basis for the effectiveness of interventions aimed at the control of aggression. The 1998 Royal College of Psychiatrists review, based on expert opinion, suggested that the following may be of use in mental health services:<sup>260</sup>
  - generation of calm environments
  - training of staff in de-escalation techniques and in restraint procedures
  - policies on the use of seclusion, especially as there is some evidence, from high-secure settings, that seclusion is used more frequently for those with learning disabilities<sup>261</sup>
  - policies and training in the use of sedation and emergency tranquillisation.

It is reasonable to suggest that these measures also represent good practice in learning disability services. A policy framework for the use of physical interventions in learning disabilities has also been published.<sup>262</sup>

- **Accommodation:** The review of general accommodation for people with learning disability (*see* 'Accommodation' above) includes a number of studies that included people with challenging behaviour as part of a general study population. Overall, research suggests that specialist staffed houses have better outcomes than hospital-based provision.

The costs for a sample of people with challenging behaviour in Wales have been reported. Care in staffed group homes was the most costly, followed by hostels. Hospital care was the least costly.<sup>263,264</sup>

There was little difference in behaviour problems between settings, despite the fact that hospital and hostel residents were more disabled in their adaptive behaviour than staffed group home residents. Process measures of quality, such as staff attention, assistance and individual orientation, were higher in staffed group homes. Preliminary results for people with learning disabilities and challenging behaviours in the former North West Regional Health Authority suggested a different cost pattern.<sup>265</sup> Costs were greatest in hospital, followed by residential care, and care in family or foster homes was the least costly.

Evaluation of specialist challenging behaviour inpatient units suggests that the frequency and severity of challenging behaviours can be reduced and the number of individuals in community placements increased.<sup>266</sup> The longer-term impact of such units is less clear, as improvements in behaviours may not be maintained on discharge. Units may become 'silted up' with long-stay clients.<sup>267</sup> An alternative to inpatient provision is to increase the competence in mainstream services using specialist intensive home support teams.<sup>70</sup> There is no evidence for the relative effectiveness of these models.

## Offending behaviours

There is relatively little evidence for the effectiveness of specific interventions for PWLD who offend.<sup>268</sup> Often offenders with intellectual impairment are mentioned as part of larger cohorts of offenders. Specific studies usually have small sample sizes.

Case studies have shown positive outcomes for inpatient treatment for individuals with mild impairment and violent, fire-setting or sexual-offending behaviours. Arsonists were over-represented in those with poorer outcome.<sup>266</sup>

There is some evidence to suggest that, for sexual offenders, individual goals can be improved through group therapy. As in non-learning disabled populations, recidivism is however high. It is suggested that

treatment packages should be holistic, i.e. address environmental issues and displacement of offending with other behaviours, rather than using simple elimination/punitive behavioural approaches.<sup>269</sup>

## Autistic spectrum disorders

### *Early intervention programmes*

Reviews of the literature conclude that:<sup>270,150</sup>

- programme evaluation is very variable and often methodologically flawed
- for most approaches, there is some evidence of effectiveness
- effective programmes often share key characteristics, such as emphasis on increasing an individual's attention to their environment, imitation and the involvement of parents
- approaches that rely on integration between children with and without ASD have shown positive outcomes for both children with ASD and their normally developing peers
- further research, which controls for confounding variables such as the degree of parental involvement and the intensity of intervention, is needed.

Overall, the evidence suggests that some form of early intervention should be incorporated into service provision, but it is difficult to recommend one model over another.

### *Auditory integration training (AIT)*

AIT involves the person with ASD listening to sessions of electronically altered music. Two randomised placebo-controlled trials from the USA and a number of case reports have suggested that AIT can significantly improve the behaviour of children and adults with autism.<sup>271</sup> This finding has not been replicated in UK controlled trials. Further studies are needed.<sup>272</sup>

## Specific restriction of activities: losses of function

### *Sensory impairments*

- **Structured teaching programmes:** There is limited case-report evidence to suggest that programmes which help the individual to deal with their disabilities (including the provision of aids) improve quality of life and may have a beneficial impact on challenging behaviours, e.g. self-injury.<sup>273</sup>
- **Multi-sensory stimulation:** The use of multi-sensory environments (MSE or Snoezelen rooms) has been advocated for PWLD, particularly for those with challenging behaviours maintained by sensory impairments. The evidence for their effectiveness is equivocal. A double cross-over study showed no effects beyond those that could be ascribed to the social interaction between participant and enabler.<sup>274</sup>
- **Accommodation:** There is some evidence to suggest that measures of quality of life are improved in small, specialist, supported housing in comparison to specialist hospital accommodation, although costs may be greater.<sup>275</sup> The costs of specialist accommodation in this study were considerably higher than those reported for more standard accommodation for PWLD in other studies.

## Restriction of participation: social consequences

### *Choice*

The opportunity to decide on which services to use is an important aspect of choice. The Community Care Act (direct payments) 1996 created new possibilities for individuals to have some control over the services provided for them. There is some evidence, however, to suggest that development in this field has been slow, particularly for PWLD, who may not have been included in local authority policies.<sup>276,277</sup>

### *Advocacy*

The provision of advocacy services is viewed positively by clients. The overall impact of advocacy on quality of life or the provision of services is not known.<sup>278</sup> Despite the significant increase in advocacy services, many PWLD still do not have contact with an advocate.<sup>73,279</sup>

### *Relationships*

There is currently little evidence to suggest that services for PWLD have been particularly effective at creating relationships for people, although as a group they may be less excluded than previously.<sup>161,280</sup>

- **Parenting:** Research on interventions to improve parenting skills is sparse and methodologically flawed. Training primary health professionals to recognise vulnerable or actual parents with learning disabilities may be of benefit. Adaptation of school-based parenting education and portage can also help PWLD to learn parenting skills.<sup>281</sup> Families are likely to need help at least until their children reach adulthood.

### *Abuse*

Despite the existence of good-practice guidance on how to deal with the sexual abuse of PWLD it has been suggested that many cases remain unrecognised, unreported or inadequately dealt with. In one study of sexual abuse, the police were only involved in 42% of sexual abuse cases which were eventually proven or highly suspected.<sup>105</sup>

## Restriction in participation: carers and families

Long-term support for carers/families has been recognised as important for coping and the maintenance of informal caring.<sup>282</sup> In one study, 60% of carers identified the need for such support, but the level of unmet need was high.<sup>26</sup> Support may involve a number of components, including information, counselling at the time of detection or training in behavioural techniques. There is some research to suggest that support may have a positive impact on family relationships.<sup>283</sup>

### *Respite care*

Reports suggest that respite care is considered important by parents as a part of their coping strategies.<sup>284</sup> However, although respite care has received increased attention, there is little information about the cost-effectiveness of different arrangements. In one study the cost per night of placement was higher in residential care (particularly in NHS facilities) compared to foster care.<sup>285</sup> Although most parents

expressed satisfaction with services, this study highlighted the trade-off between the welfare of parents and that of the children. A number of more recently developed respite care schemes providing activities, special clubs and outdoor pursuits have been described.<sup>286</sup> Most schemes focused on short-term relief, although some offered night cover. Cost-effectiveness cannot be determined, as the impact on utilisation of other services or on family costs was not calculated.

## Conclusions

The literature on the effectiveness of treatments, interventions and service models for PWLD is mainly limited to descriptive and uncontrolled research studies. By far the largest body of work is in the field of accommodation and behavioural interventions. Despite this there remains significant uncertainty. Which model of accommodation or behavioural intervention is best for any particular individual? Further research to allow better tailoring of interventions for individuals is needed. Table 9 outlines key areas of knowledge on effectiveness.

**Table 9:** The effectiveness of services/interventions for people with learning disabilities.

Service/intervention	Comment
Accommodation	
Small dispersed housing vs. other provision	Measurable benefit from descriptive and well-designed uncontrolled studies
Non-hospital village communities vs. other provision	As above
Residential care for children	Inadequate and conflicting, but with some expert opinion in favour
Respite care for children	Inadequate and conflicting, but with some expert opinion in favour
Daytime activities	
Supported employment	Measurable benefit: III
Antipsychotic medication	
Schizophrenia	Measurable benefit for some: III
Challenging behaviours	Measurable benefit for some: IV
Psychotherapeutic interventions	
Behavioural approaches	Measurable benefit: II-1
Other	Measurable benefit: II-1
Challenging behaviour and behavioural approaches	Measurable benefit: II-1

For a description of allocated quality of evidence, see Introduction to this series.

## 7 Models of care

### Components of a comprehensive learning disability service

A systems approach to service provision is necessary if comprehensive, integrated and inclusive services are to be provided. Processes of care, such as the nature of inter-agency working, as well as structural elements

will determine the adequacy of local service provision. It is likely that the technical ability of staff will be a greater determinant of local service capacity than the availability of specific settings. It is therefore not possible to examine one element of a service in isolation. For example, the need for hospital beds will be determined by the capacity of community services to prevent admissions and expedite discharge as well as the number of PWLD in the population. For these reasons, and the dearth of relative effectiveness data for different models of provision, it is not possible to make recommendations to define a model service. It is possible, however, to outline both structural and process components of services that should form the basis for local planning discussions. Local providers and commissioners may then determine the most appropriate local configuration of structure and process needed to achieve a comprehensive service. This necessitates partnership working at all levels and between all of the relevant agencies.

It is possible to separate out issues at population and client levels, although clearly there is overlap.<sup>287</sup> Population need for services is discussed first, followed by client need for services. The various subsections consider elements of structure, process and outcome and should be considered in conjunction with Sections 5, 6 and 8.

## Population need for services

At a population level the elements of a comprehensive service may be thought of in the following categories:

- planning, including needs assessment and service development
- inter-agency working, including consultation and liaison across services
- service provision, covering health promotion, primary, secondary and tertiary health care, social care, housing services, self-help, etc.
- organisations that are fit for purpose.

### *Planning and inter-agency working*

#### **Structures**

Inter-agency planning forums with responsibility for the full population age range (i.e. child and adolescent, adult and elderly) should be in place. All relevant stakeholders should contribute to the work of these forums. In addition to specialist learning disabilities services, there should be representation from or defined ways of consulting with the following groups: clients, carers, independent sector, criminal justice system, housing, education, employment services, primary care services, mental health services, acute medical and community health services, e.g. physical disability teams and neurology services.

A number of mechanisms for consultation exist:

- direct representation on committees/groups
- cross-representation between groups/committees
- formal consultation processes, e.g. rolling search conferences/focus groups
- individuals with designated responsibility to consult with/advocate for particular stakeholders.

Guidance on the involvement of PWLD in the commissioning of services has been published.<sup>288</sup>



**Table 10:** Predicted numbers of people with learning disabilities and other conditions in a population of 100 000.

Condition	Predicted numbers per 100,000
Mild intellectual impairment IQ < 70, prevalence of 2.75%	2,700
Mild learning disabilities Prevalence 1–2%, depending on definition	1,000–2,000
Severe intellectual impairment IQ < 50 and others with coexisting conditions, prevalence 0.3–0.4%	300–400, of whom 75–100 will be < 16 years and 225–300 will be adults
Down's syndrome Prevalence 30% of severe learning disability 10% given up at birth 10% full-time or part-time care required in childhood	90–120
Challenging behaviours Point prevalence of significant challenge	20
Challenging behaviours Point prevalence of all those that may present difficulties to carers or risk to themselves	100
Autistic spectrum disorder Whole spectrum	910
Autistic spectrum disorder, IQ < 70: Classical (Kanner's) autism	50
Other spectrum disorders	150
Autistic spectrum disorder, IQ > 70: Asperger's syndrome	360
Other spectrum disorders	350
Epilepsy Severe learning disabilities and epilepsy	54–72
Epilepsy Profound learning disabilities and epilepsy	22–30
Cerebral palsy and severe learning disabilities	92–136

### Processes

- **Macro needs assessment (commissioner led):** This should include the following areas.
  - Baseline description of population demography and delineation of local high-risk groups.
  - Baseline epidemiological prediction of numbers of PWLD in the population, using projections of national data or local research (*see* Table 10). Local sociodemographic and service factors that should be considered are the birth rate, uptake of screening and selective termination, ethnic minority groups, the rate of resettlement of the long-stay population, the numbers of PWLD in high-secure hospitals, the adequacy of local case finding and local migration over the past 50 years.
  - Profiling the age and needs of individuals coming up to transition from child to adult services.
  - Making predication from the age structure of local PWLD on the likely future numbers of dementia sufferers.
  - Profiling local PWLD according to categories of need, e.g. accommodation, leisure, employment, physical and mental health (i.e. using information from person-centred planning).
  - Profiling the age and needs of carers to help inform service planning for carers and transition planning as they age.<sup>289</sup>

- Baseline understanding of all sectors' current resources, including staff numbers and skills, and the identification of current spend within statutory agencies, including housing.
- Identification of gaps in funding/service provision.
- **Micro needs assessment (provider led):** This should include:
  - analysis of case loads/service demands across teams/services
  - analysis of skill-mix across teams
  - analysis of assessments of carer needs
  - collation of information from person-centred care planning to generate profiles of need
  - application of population needs assessment work to the determination of local service configuration.
- **Partnerships:** Specific work is needed to ensure that, at a population level, there are no gaps in service provision and that consultation and liaison about individual clients can occur with relative ease. A number of approaches may facilitate this:
  - agreed processes for referral
  - agreed standards for referral
  - named responsibility at both clinical and managerial levels for ensuring development and review of consultation and liaison structures and processes
  - development of inter-agency registers of PWLD, shared with primary care
  - development of information systems shared across agencies.
 Formal agreements between specialist learning disability service providers and other providers/agencies may be of benefit.
- **Social/health care:** Agreement on the relative roles of health and social care providers in the management of the spectrum of learning disabilities and other coexisting conditions.
- **Primary/secondary care providers:** Agreement on shared care issues, e.g. prescribing costs, drug monitoring, physical health screening and monitoring, family planning. Agreements on how to improve access to generic services.
- **Other services (e.g. residential homes, educational establishments and day-care facilities):** Agreements on the level of support provided to them by specialised services, e.g. training.
- **Mental health services:** Defined responsibilities are particularly important at the boundaries of services. The following groups of PWLD merit specific local discussion between specialist mental health and learning disability services if they are to receive adequate service provision: mild and borderline learning disabilities, ASD (including Asperger's syndrome), the transition years (adolescence and the elderly), early-onset dementia, brain injury, challenging behaviours, mental illness and physical disabilities.
- **Generic medical and surgical specialities:** The organisation of support and information so that they are accessible to PWLD should be agreed.
- **Paediatrics/child development and child and adolescent mental health services:** Their relative roles and contributions should be defined.

### Outcomes

Needs-based, person-centred planning and effective inter-agency working should help to develop local strategic and operational thinking leading to the following.

- Joint strategies with targets for service development/spend. The over-arching learning disability strategy will need subsections, or separate inter-linking strategies, to cover specific services/populations, e.g. offenders/primary care/housing.
- Staff and other resources within services can be deployed according to local need.

*Health service provision: general population health promotion and disease prevention***Structures**

- Genetic counselling.
- Screening programmes: local policies should ensure that screening protocols are appropriate, understood by staff and do not include unnecessary duplication of tests.
- Immunisation programmes.
- Accident prevention strategies.

**Processes**

- Folate and alcohol advice in antenatal and primary care settings.
- Appropriate information and counselling of parents undergoing prenatal testing.
- Sensitive disclosure policies covering all relevant services, e.g. children's services.

**Outcomes**

Reduction in the incidence of intellectual impairment, in the severity of disabilities and their associated disadvantage.

*Health service provision: primary care***Structures**

- Practice registers of PWLD and their needs.
- Screening programmes: hypertension, mental ill-health, thyroid function, etc.
- Primary care services, e.g. continence, chiropody, dentistry, pharmacy and dietetics, that have experience in dealing with PWLD.

**Processes**

- Annual physical, dental and mental health reviews.
- Support to carers/families, e.g. access to counselling services.

**Outcomes**

- Reduction in the amount of unrecognised physical and mental ill-health in PWLD.
- Improvements in the well-being of carers/families.

*Health service provision: specialist learning disability services*

Specialist services, provided by whichever sector is most appropriate, will need to make provision for:

- assessment, detection and diagnosis
- treatment and continuing care
- consultation and liaison.

## Assessment

### *Structures*

- **Multi-disciplinary/inter-agency locality-based teams:** Local circumstances will dictate the precise organisation.
- **Crisis intervention services:** These should be available during and outside office hours and should include arrangements with the criminal justice system, such as the provision of appropriate adults.

### *Processes*

- Multi-disciplinary assessment based on comprehensive functional analysis.
- Person-centred care planning.
- Crisis intervention.
- Support for individuals to help them access generic services.
- Carer information and support.

### *Outcomes*

- Appropriate and timely assessments.

## Treatment and continuing care

### *Structures*

- **Community follow-up:** Follow-up settings should be those most appropriate for the client.
- **Day care:** The distinction in use between health-based and day-centre care is important. Health-based day care should be provided when a clinical component is required and not simply daytime activity. This will only be needed for a very small number of PWLD.
- **Inpatient facilities:** A range of health care beds is required covering assessment, treatment and continuing care for a small number of individuals with complex disabilities, such as those with challenging behaviours who need a secure setting. Facilities should provide the least restrictive and most safe, homely and local environment for the client.

### *Processes*

- **Case management:** The principles of key working, care planning and review should apply. This should include liaison over out-of-district placements.
- **Crisis intervention:** Identification of triggers to challenging behaviours or crisis and the development of crisis plans.
- **Psychological interventions:** At least the following types of interventions are needed, underpinned by functional analysis: group and individual therapies, cognitive/behavioural therapies, family interventions and counselling, e.g. for bereavement, families, in cases of abuse.
- **Speech and language therapy interventions.**
- **Occupational therapy interventions.**
- **Physiotherapy interventions.**
- **Pharmacological treatments.**

*Outcomes*

- Individualised care plans.
- Improvements and/or prevention of deterioration in symptomatology and social functioning.
- Prevention of abuse.

**Consultation and liaison***Processes*

- Support to primary care and other community services.
- Teaching to a spectrum of care providers.

*Outcomes*

- Improved access to and uptake of generic services.
- Improved understanding of the issues relating to learning disabilities in non-specialist providers.

*Organisational competence*

An in-depth discussion of this issue is outside the remit of this chapter. Key issues that should be considered include the following:

- the generation of a joint value base and of operational policies that are shared across agencies, e.g. on dealing with abuse
- structures and processes that encourage partnership and joint working between staff in different agencies
- teambuilding
- training, e.g. the availability of specialist skills nursing – RNLD enhanced by ENB accreditation in challenging behaviours or mental health
- the determination of clinical outcomes of care.

**Client need for services**

All clients will have some basic shared needs, irrespective of disability. Some of these will be met by specialist services, some by carers/families and some by other service providers. The level of disability, coexisting conditions and family circumstances are likely to dictate in which cases service provision is required in order that needs are met. A client's need for services may be for any or all of the following:

- daytime activity
- a home/accommodation
- information and support, including an income
- health and social care (*see* 'Health service provision' above).

Other needs, such as the need for relationship or respect, as outlined by O'Brien's five accomplishments, should inform all aspects of service provision.

### *Daytime activity*

Guidance on the development of daytime activity has been published.<sup>136</sup>

#### **Structures**

- Day centres.
- Drop-ins.
- Employment schemes, including open employment, various types of supported employment and sheltered work schemes.
- Education ranging from pre-school programmes through formal mainstream schooling to specialist provision to adult and further education.
- Leisure activities.
- Befriending schemes.

#### **Processes**

- Social network development.
- Social skills development.
- Training and personal development.
- Meaningful/gainful employment.

#### **Outcome**

- Improvements in individuals' quality of life.

### *Accommodation*

Whenever possible, supported independent living in ordinary homes should be the goal. Specialist accommodation and support may be needed for those with challenging behaviours, physical and sensory impairments, mental illness and ASD.

#### **Structures**

A range of accommodation is needed, including:

- day-staffed accommodation
- group homes with staff visiting daily
- group homes with staff on call
- supervised private lodgings
- own tenancies
- respite care
- specialist health care provision.

#### **Processes**

- In-home support, ranging from help with assessment and budgeting and help in carrying out activities of daily living to engaging in leisure activities.
- Home alterations for those with physical/sensory disabilities.
- Specific programmes of interventions for those with specialist needs.

**Outcomes**

- Individuals live in environments that are as close to ordinary homes as possible.

*Information and support*

These services are as important for carers and families as they are for clients.

**Structures**

- Advocacy services.
- Benefits advice services.
- Parenting education and support services for prospective and actual parents with learning disabilities.

**Processes**

- Information given in appropriate formats.

**Outcomes**

- Empowerment of individuals.
- Reduction in the stress of caring.
- Reduction in the levels of abuse, neglect and developmental delay in children of parents with learning disabilities.

**Levels of provision***Background*

Planning targets for learning disability services were set nationally in 1971.<sup>290</sup> The nature of service provision has changed to such an extent since this time that these norms are no longer applicable. A number of local needs assessment exercises have attempted to redefine appropriate levels of provision (*see* Table 11).<sup>187,291</sup>

**Table 11:** Estimates for local provision for adults with learning disabilities, aged > 20 years (excluding provision for mental illness, offending and challenging behaviours).

	NHS	Non-NHS
Residential care places	47/100,000	103/100,000
Day-care options, including employment		224/100,000
Respite care placements		36/100,000

Source: McGrother *et al.*<sup>291</sup>

### *Accommodation*

It is important to recognise the changing need for accommodation over time both for the whole population of PWLD and for any one individual. A model that attempts to capture some of this complexity has been developed.<sup>131</sup> This model suggests that, over a five-year period, the following proportions of a local population of adults with learning disabilities (excluding those in hospital provision) will need new accommodation.

- **PWLD living with elderly carers:** 10% owing to carer stress/ill-health or other crisis and 10% planned move to avert crisis.
- **PWLD with younger carers:** 10% owing to carer stress or other crisis and 10% to accommodate the need for independent living.
- **PWLD in social services-run hostels:** 29%.
- **PWLD in other hostels:** 30%.
- **PWLD in nursing/residential care:** 10%.
- **PWLD living in their own tenancy:** 10%.

The relevance of the model is in thinking coherently about planning housing options. The actual percentages in the different groups may well vary in different populations.

### *Professional groups*

A number of professional organisations have made suggestions for appropriate levels of input to local services.

- **Psychiatry:** One WTE consultant/100 000 for general learning disability services. Additional consultant input will be required for forensic and children's services.<sup>292</sup>
- **Psychology:** Four WTEs/250 000 are recommended for general adult learning disability services, with a B-grade consultant clinical psychologist heading the service.<sup>293</sup> Additional input of at least 1 WTE/75 000 general population will be required to work with 0–19-year-olds and their families. Similarly, a B-grade consultant child psychologist should head the service.<sup>294</sup>
- **Nursing:** There are no recommended levels of provision.
- **Occupational therapy/speech therapy/physiotherapy:** There are no recommended levels of provision. The perception is that many services do not have sufficient input and posts are often difficult to fill with appropriately trained staff.

## **Conclusions**

Commissioners of services for PWLD need to recognise the range and complexity of the condition and consequently the inevitable complexity and variability of the system that will be needed to meet these needs. The level at which commissioning is carried out may well be different for discrete aspects of the condition. Individualised packages and joint funding will be needed for those with the most complex needs. Challenging behaviour and sensory impairment services may well need to be purchased at population levels larger than the average PCT in order to ensure service integrity and expertise. Prevention services and primary care can more easily be provided and commissioned for smaller population groups. The capacity for flexible, local approaches is likely to produce the most comprehensive commissioning and development of services.



## 8 Target setting

### Introduction

The precise nature of local targets will be determined by the current nature of provision and local data collection capabilities. They should, however, be aimed at attempting to improve quality of life and reduce social exclusion. Targets should be reflected in local strategies. The targets may be set with respect to the structure, process and outcome variables discussed in Section 7.

The process of target setting may be helped by:

- local discussions between commissioning and provider managers and clinicians
- an understanding of local epidemiological data
- development of local policies and implementation plans, which include relevant time-scales and training
- review of the implementation of policies
- including local service and policy development in audit programmes.

The following subsections list areas in which local targets may be set covering the incidence of learning disabilities, the health of PWLD and the services that are provided for them.

### Health promotion

#### *Primary and secondary prevention*

- Targeting of genetic counselling programmes.
- Coverage of screening programme for Down's syndrome and the rate of detection against incidence.
- Coverage of PKU and congenital hypothyroidism screening (Guthrie test).
- Birth frequency of low and very low birth weight babies, corrected for gestation.
- Reduction in the incidence of NTDs and of cerebral palsy.
- Reduction in the incidence of severe head injuries.

#### *Physical and mental health of PWLD and their carers*

- Rate of uptake of health promotion services, e.g. CVD, breast and cervical screening.
- Improvements in screening for mental ill-health.
- Reduction in levels of obesity.
- Reduction in levels of untreated hypothyroidism in people with Down's syndrome.
- Prevalence of and uptake of screening for hepatitis B and C.
- Improved rate of detection of sensory impairments.
- Reduction in mortality/morbidity associated with seizures.
- Reduction in prevalence of challenging behaviours.
- Reduction in levels of abuse.
- Reduction in the levels of prescribing of antipsychotic medication.
- Increased identification of parents with learning disabilities.
- Reduction in the levels of neglect, abuse and developmental delay in children of parents with learning disabilities.
- Increased use of facilities available to the general public, such as education, leisure and recreation.
- Reduction in the ill-health of carers.

## **Accommodation**

- Increases in the numbers of PWLD who are in supported independent living.
- Reduction in the numbers of PWLD accommodated in long-stay hospital beds.
- Reduction in the numbers of PWLD accommodated in out-of-area placements.

## **Daytime activities**

- Reduction in the numbers of PWLD who do not have organised daytime activities, whether employment/training/education or leisure.
- Reductions in school exclusions for children with learning disabilities.

## **Information and support**

- Development of local information in appropriate formats.
- Increases in users' and carers' satisfaction with services provided.
- Increases in social networks.
- Improvements in the availability of respite care.
- Improved access to advocacy services.

## **Specialist services**

- Development of expertise/specialist services for mental illness, challenging behaviours, ASD and complex disabilities, including sensory impairments.
- Staff training – increases in the proportion of staff with appropriate specific training in the management of mental ill-health and challenging behaviours in PWLD, e.g. training in de-escalation and restraint procedures and in behavioural interventions.

## **Commissioning**

- Development of joint strategies with education, housing, specialist services, primary care and relevant acute services.
- Development of joint budgets.
- Development of direct payment schemes.
- Development and maintenance of local inter-agency registers of PWLD.
- Development of standards and the systematic collection of information with which to monitor services.
- Increased involvement of users and carers in the planning and evaluation of services.

For further discussion on target setting, see the All Wales Health Gain Protocol.<sup>2</sup>

## 9 Information and research requirements

### Data sources

Routine data sources are limited in their usefulness. The extent to which data can be disaggregated to client group or further to severity is very variable. Furthermore, information on a large number of services necessary for rounded provision is unavailable, e.g. employment or leisure services.

This section indicates routine sources which may be helpful.

#### *Health service*

Development of a learning disabilities minimum data set is ongoing.

#### National data sets

- Bed numbers: no categorisation other than long/short-stay and secure.
- Completed consultant episodes: of limited use, as there are shifts away from inpatient care and lengths of stay are very variable.
- Community nurse contacts.

#### Local data

Some information may be available from primary care and nursing homes registers.

#### *Social services*

##### National

- Residential and nursing home places where they are designated for PWLD.
- Day-care places.
- Home help/home care usage.

##### Local

- **Registers:** About 60 local authorities hold registers. They are very variable in quality, with no standardised format, and only count those in contact with services. Their accuracy is dependent on notification, which is often incomplete. Where they are well kept they provide extremely helpful information. There is no central collation of information from registers.

#### *The OPCS Disability Survey*

This provides some useful information on activities of daily living and services. There are, however, criticisms of the criteria used to determine type and level of disability. The last survey was carried out in the mid-1980s. This also limits its usefulness, given the significant shifts in provision since that time.

## *Education*

### **National**

The Education Act 1981 abolished existing specific categories of handicap in favour of emphasis upon special educational need, which therefore covers learning disabilities, sensory impairments and emotional and behavioural problems. As a result, national data may not be very helpful, as learning disabilities cannot be identified as a separate group.

### **Local**

- Numbers of children with statements of special educational need.
- School exclusion data.
- Placements in special schools.
- Home tuition numbers.
- Pre-school programmes.
- 14+ transition plans.

## **Research**

This chapter highlights the paucity of research into many aspects of learning disabilities. An extensive research programme is required, ranging from the aetiology of learning disabilities to the effectiveness of service interventions. Some broad categories of research are outlined here.

### *Aetiology*

- Exploration of the links between prenatal damage and birth trauma.
- Causation of mild learning disabilities.

### *Primary care*

- Increased knowledge about health promotion activities in general, including evaluation of models to increase uptake.
- Appropriateness and effectiveness of screening programmes, e.g. cervical and cardiovascular screening.

### *Accommodation*

- Effectiveness of home-based care packages.
- Cost–benefits of residential care options, including village communities.

### *Daytime activities*

- Cost–benefits of the provision of various options from leisure to education and employment.
- Evaluation of techniques to maintain employment for PWLD.

### *Information and support*

- Evaluation of different types of respite, their costs and their impact on carer and client well-being.
- Further development of specific, user-friendly quality-of-life measures.

- Use of the general population as a comparator in quality-of-life/satisfaction studies.
- Evaluation of methodologies to include user/carer views in service planning and evaluation.
- Evaluation of policies to increase community participation/social inclusion.

### *Service models and interventions*

- Improved knowledge of the relative cost-effectiveness of different service models.
- Improved knowledge of the effectiveness of early interventions.
- Improved knowledge of the relative benefits of models of provision, such as specialist services for sensory impairment and challenging behaviours, including forensic care.
- Long-term outcomes for behavioural treatments for challenging behaviours.
- Impact of other psychotherapeutic interventions.
- Effectiveness of interventions, particularly early intervention, and of care environments for people with ASD.
- Effectiveness of the therapies (occupational, physiotherapy and speech and language therapies) in the learning-disabled population.
- A greater understanding of the usefulness of/indications for antipsychotic medication.

## Appendix I: Health and social care for PWLD

It is generally agreed that health and social care needs cannot be easily separated. At a pragmatic level it may be possible to describe an individual's needs in three ways:

- universal
- additional
- special.

For PWLD these categories can be further described as follows:

- universal, e.g. a place to live, financial security, friendships, the opportunity to have a meaningful day
- additional needs arising from learning disability, e.g. help with mobility, help to access services, help to understand information, help with communication
- special needs, e.g. support in crisis situations, treatment to improve mental health or to help to reduce challenging behaviours.

For any one of these needs, the level of support required may vary. An individual may need limited, intermittent or extensive support.

- **Limited support:** This may be of high or low intensity and complexity. It is time-limited or limited by some other resource constraint and is typically applied at transitional periods.
- **Intermittent support:** This may be of high or low intensity and complexity. It is characterised by its ongoing nature and is applied for a specific purpose or to provide general support for an individual on an as-needed basis. It may also be required to support someone in a specific setting.
- **Extensive support:** This is characterised by its intensity, complexity and consistency across different settings.

A matrix can be devised from these categories. This can help to delineate where responsibilities may lie for carrying out health and social care functions rather than indicating whether these functions should take place in a health or social care setting.

Type of support	Type of need		
	Universal	Additional	Special
Limited	Social care	Social/health care	Social/health care
Intermittent	Social care	Social/health care	Health care
Extensive	Social/health care	Social/health care	Health care

Source: Adapted from Turnbull J and Cullen C. *A Report for Bromley Health Authority* 1998.

It is therefore the case that either health or social care agencies, or both, may meet many of the needs of PWLD.

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