

# ANNEX VIII: THE UNITED KINGDOM<sup>1</sup>

## 1 BACKGROUND

### 1.1 Terminology and definition

The term ‘intellectual disabilities’ is increasingly used in international academic journals. Within the UK the term most commonly used is ‘learning disabilities’. This term was first used officially in 1991 by Stephen Dorrell, then Minister of Health in a speech to MENCAP. Terms used previously to describe this group, such as ‘mental handicap’, ‘mental retardation’, ‘mental subnormality’ and ‘mental deficiency’, are now considered to be disparaging. The term ‘learning difficulties’ is used in the education system and by some health and social care professionals and agencies. Some self-advocates, that is people with intellectual disabilities themselves, also prefer this term. However, ‘learning difficulties’ is confusing because it is sometimes understood, particularly in the education field, to have a broader meaning. For example, children with dyslexia may be said to have learning difficulties but would not be considered as having an intellectual disability.

The Diagnostic and Statistical Manual (DSM IV) of the American Psychiatric Association defines intellectual disability in terms of significantly sub-average general intellectual functioning (an IQ of 70 or below, with concurrent deficits or impairments in adaptive functioning) and onset before the age of 18 (American Psychiatric Association, 1995). The American Association on Mental Retardation defines intellectual disability in essentially the same way except that the IQ range is wider (IQ<75) and the definition includes examples of adaptive skill areas, deficiencies in two or more of which, together with onset before the age of 18, constitutes learning disabilities (Luckasson et al., 1992). Intellectual disability is usually subdivided according to level of severity. The World Health Organization diagnostic categories in the ICD-10 clinical descriptions and diagnostic guidelines are as follows: mild (IQ=50-70), moderate (IQ=35-49), severe (IQ=20-34), profound (IQ<20) (World Health Organization, 1992).

### 1.2 Historical context of services

Over the last 35 years in the UK there has been a major change in the nature of residential service provision for adults with intellectual disabilities. Residential services were once characterised by the congregation of large numbers of people with learning disabilities in isolated settings. Institutions used to be run by a single agency, initially local authorities and then health authorities. For many years they were operated behind closed doors. The eventual exposure of the poor conditions within institutions was a major catalyst for the development of community residential services (Felce et al., 1998). Today, residential services are provided by a variety of agencies including private and voluntary bodies as well as the statutory sector. Typically, they cater for small groups of people in ordinary houses located within the general community. Day services have undergone a similar transition. Initially, day activities tended to be operated from within the large institutions in which many people lived. This type of day occupation had its roots in agricultural activities within the land which typically surrounded the institutions and was aimed at reducing the economic burden which large institutions had on society. The emphasis of such services gradually shifted to ‘industrial’ therapy. As institutional provision contracted, day services were provided within the community. Despite their community location, large numbers of people with intellectual disability were congregated in these ‘adult training’ or ‘social education’ centres.

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<sup>1</sup> This report draws heavily on the following sources:

(a) Beyer, S., Banks, P., McConkey, R., Dunlop, E., & Morgan, H. 2005. Rights of people with intellectual disabilities: Access to education and employment. Eu Monitoring and Advocacy Program Open Society Mental Health Initiative.

(b) Kerr, M., Felce, D. and Felce, J. 2005. Equal treatment: Closing the gap. Final report from the Welsh Centre for Learning Disabilities to the Disability Rights Commission.

More recently, such centres have often become administrative bases from which more integrated activities (e.g., work experience and college courses) are organised and co-ordinated. In addition, there has been a growth of ‘supported employment’ agencies which have the aim of finding people paid employment, supporting them to do the work within the actual work setting, and supporting them to keep jobs. As with residential and day services for adults, services for children have been influenced by Wolfensberger’s principle of normalisation. Consequently, whilst children with intellectual disability were once educated in segregated ‘special’ schools, there is greater emphasis now on ‘inclusive’ education in mainstream schools.

### 1.3 Rights

The UK has ratified most international human rights instruments, including those with provisions relating to the rights of people with disabilities. However, the UK has yet to ratify the revised European Social Charter, or to sign and ratify Protocol No. 12 to the European Convention on the Protection of Human Rights and Fundamental Freedoms (ECHR). It has also not ratified ILO Convention C159 on Vocational Rehabilitation and Employment (Disabled Persons), 1983.

From May 1997, the UK Government introduced devolution of powers to Scotland, Wales and Northern Ireland, with the Westminster Parliament retaining sovereignty for areas such as foreign affairs, defence and macro-economic policy. The Scottish Parliament and the National Assembly for Wales (NAfW) assumed their responsibilities in 1999. The Northern Ireland Assembly was suspended in 2002. Although a ‘virtual assembly has been meeting since May 2006, the passing of legislation in Northern Ireland remains under the control of ministers in London. Unlike most European countries, the UK does not have a written Constitution, but the UK has a comprehensive legislative framework to counter discrimination and ensure equal rights.

The Human Rights Act 1998 includes a prohibition of discrimination, although not explicitly on the grounds of disability. The most important legislation on the rights of people with disabilities is the Disability Discrimination Act 1995 (DDA). This provides a definition of disability, and measures to prevent discrimination on the ground of disability in the areas of employment; access to goods, facilities and services; and buying or renting land or property. The DDA was extended to cover education (in schools and further and higher education) through the Special Educational Needs and Disability Act 2001 (SENDA 2001). In the area of employment, it was further amended through the Disability Discrimination Act 1995 (Amendment) Regulations 2003 (DDA Regulations 2003), which entered into force on 1 October 2004. The Disability Discrimination Act 2005 (DDA 2005) will in December 2006 create a “Disability Equality Duty” on Public Sector organisations to counter discrimination in employment and to actively promote disability equality in all aspects of their work. The DDA and subsequent amendments apply to England, Wales, Northern Ireland and (with minor exceptions) to Scotland. There are regional amendments to DDA which apply to different UK jurisdictions. The DDA 2005 does not fully extend to Scotland and Northern Ireland, but the Scottish Parliament is to legislate to ensure all its additional features are provided there. Local Education Authorities are responsible for assessing the Special Educational Needs that result from any disability, intellectual or otherwise.

Guardianship is infrequently used in the UK and, where it is, it is rarely used for people with intellectual disabilities. In England there were only 473 new cases of guardianship in 2004, of which the majority concerned people with mental health problems. In all cases, the guardian was the Local Authority. It is important to note that in the UK, guardianship is a very different power than in many other European countries, and it is not linked to an individual’s capacity. In England and Wales, the Mental Health Act 1983 defines guardianship. A guardian only has three powers; to require the person under guardianship to reside at a specified place; or attend specified places for medical treatment, occupation, education or training; and to require access be given to the individual by a doctor, approved social worker or other specified person. The Mental Capacity Act 2005, which will not enter into force until 2007, will in future provide a comprehensive legislative framework for decision-making on behalf of people who lack the

capacity to make decisions for themselves. In Scotland, legislation improving the protection of the rights of adults who lack the mental capacity has already been enacted.

#### 1.4 Prevalence<sup>2</sup>

In the UK, most official data on people with disabilities is not disaggregated by type of disability, so it is difficult to find precise information on people with intellectual disabilities. In education, for example, data on children and young people with special educational needs does not reveal specific details on children with intellectual disabilities. The 2001 National Census did include questions on respondents' state of health and whether they had a limiting long-term illness, however, again, specific information on people with intellectual disabilities is not available.

Epidemiological studies of intellectual disability typically use IQ assessments to classify a person as having either mild or severe intellectual disabilities, rather than the four-level classification, using a combination of IQ score and adaptive behaviour assessments, recommended in international standards such as the ICD-10. The birth prevalence of intellectual disability is difficult to estimate, as it is not until later in life when IQ can be tested, when characteristic delays in social functioning and adaptive skills become clear. Only a proportion of the conditions associated with even severe intellectual disabilities are identifiable at birth. Typically, the age-specific prevalence of severe intellectual disability grows through the preschool and school years, as children are identified.

Estimates for the UK at the beginning of the 1990s suggested that there were about five people with severe intellectual disabilities per 1,000 of the total population aged 15-24. Allowing for mortality during childhood, this gave an estimated birth prevalence of at least six per 1,000. The overall prevalence rate for people with severe intellectual disabilities was estimated at between three and four per 1,000 of the total population, (probably in the region of 360-380 per 100,000). Applied to the population of the UK<sup>3</sup> such a rate would have suggested that there were about 221,000 people with severe intellectual disabilities.

Population screening studies yielded prevalence rates of mild intellectual disability of about 25-30 people per 1,000 of the total population. This is much higher than those given by studies using administrative populations (based on information from agencies providing specialist services to people with intellectual disabilities), which indicate less than ten per 1,000. The former figure is approximately what would be expected given a normal IQ distribution. Including a measure of adaptive behaviour (such as whether a person could dress themselves or prepare a basic meal) would be likely to reduce such a rate considerably, in line with the lower administrative prevalence. This translates into around 600,000 people in the UK with mild intellectual disabilities.

Overall, therefore, around 820,000 people in the UK have intellectual disabilities according to the definitions presented above. However, it is fair to say that estimates do differ and that there is no definitive estimate of the number of people with intellectual disabilities in the UK. Estimates range up to two million for people with all forms of intellectual disability (Foundation for People with Learning Disabilities, 2001).

## 2 Service Provision

### 2.1 Residential services

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<sup>2</sup> This section is informed by: Learning Disability Advisory Group, Fulfilling the Promises, section 4.

<sup>3</sup> For mid-2004 the total population of the UK was approximately 59,834,300. Information from the National Statistics website, available at <http://www.statistics.gov.uk> (accessed 7 June 2006).

In Wales, the All Wales Strategy for the Development of Services for Mentally Handicapped People (AWS) (Welsh Office, 1983) was launched by the Welsh Office to reorientate services away from traditional models towards new forms of community provision. It sought the development of locally available, community-based residential, day, family support, respite and professional services as well as wider use of generic services and better access to the ordinary resources of the community. This national strategy was underpinned by a set of principles which stressed that services should be geared towards the promotion of lifestyles typical of the general population, the treatment of people as individuals and the maximisation of personal development. A central plank of the AWS was the designation of social services departments as the lead agency responsible for service coordination and development. The adoption of a social care model to replace the prevailing medical model had been advocated for some time (Department of Health and Social Security, 1979; King's Fund, 1980; Welsh Office, 1978) but the AWS was the first policy to prescribe this. It did not happen in England until the NHS and Community Care Act (NHSCCA) (Department of Health and Social Security, 1990). In respect of residential services, the aims of the NHSCCA were similar to those of the AWS, although arguably, it detracted from the consumer-driven needs led approach espoused in the AWS (Felce et al., 1998 p.206). In addition, the NHSCCA created a split between service purchasers and providers.

A consequence of the AWS and NHSCCA was the widespread development of alternatives to institutional living. Small scale, staffed housing, based in the community, is now the dominant form of residential service provision in Britain for people with intellectual disabilities. Over the 29 years between 1969 and 1998 the adult specialist hospital population in England fell by 88% from 49,200 to 5,940 (Department of Health, 2000; Department of Health and Social Security (DHSS), 1971; Mansell, 1997). In England, between 2004-2005 (the most recent published data available) the average daily number of places occupied by adults with intellectual disabilities in long stay hospitals was 2,561 (Department of Health, 2005). This is about a quarter of the average hospital population for the period 1993-1994. A report on the progress of the Valuing People strategy, said that in March 2005 there were less than 450 people in 15 hospitals in England and, in a response to a Parliamentary Committee, that all but one hospital would be closed by March 2006 (Department of Health, 2005). Small scale community provision has expanded commensurately. Data from the statistics unit of the Department of Health illustrates this tendency. On 31 March 2001, there were 44,130 places in staffed residential homes for adults with intellectual disabilities, of which 9,740 places were in homes for three people or fewer (Government Statistical Service, 2006). The number of places in these small group homes increased by more than 300 per cent, between 1994 and 2001. Thus, in addition to the trend for community-based residential services, these settings are now smaller than in the past.

In Wales, particularly since the late 1980s, residential service provision has also changed dramatically. The health authority share of the market in Wales fell by 31% between 1987 and 1995, local authority provision remained constant, and private and voluntary sector provision rose by 9% and 22%, respectively. An estimate for 2003-04 suggests that there were 220 people with intellectual disabilities living in long-stay hospitals (Welsh Assembly Government, 2004). Between 1987 and 1995, the mean size of residence decreased from 8.2 residents per local authority setting to 4.3, from 14.2 to 2.8 in privately operated settings, and from 11.2 to 2.8 in voluntary sector settings (Perry, Beyer, Felce, & Todd, 1998).

In Scotland, the number of people with intellectual disabilities in hospitals decreased from nearly 6,500 in 1980, to fewer than 2,450 in 1998 (Scottish Executive, 2000, p.9). There has been a programme of hospital closures across the country with a view to closing all long-stay hospitals by 2005, and recent estimates for 2004 suggest that there were 899 people with intellectual disabilities living in hospital (Scottish Executive, 2004). The reduction of the number of people in hospital has been matched by an increase in the number of people in nursing and residential care homes, and in informal supported accommodation.

In Northern Ireland, there are around 450 people living in long-stay accommodation (Bamford, 2004). The predominant model of residential provision is in registered care homes or nursing

homes with an average of 19 persons living in one building. However more adults continue to live with family carers than in Great Britain and the Republic of Ireland (McConkey, Barr & Slevin, 2004). Until recently, the birth rate has been higher in Northern Ireland with consequently more children requiring specialist services than elsewhere in Great Britain.

The policy of not providing for children in large hospitals has led to virtually no young people being provided for in this way. The largest form of congregate care used today for children with intellectual disabilities is in residential special schools. In the UK the vast majority of children with intellectual disabilities live with their parents. The term “looked after” is generally applied to children who do not live with their natural families. Data specific to children with intellectual disabilities is not readily available. In England, as of 31 March 2002, an estimated 57,400 children were looked after by local authorities (Department of Health, 2002). Of these, four per cent (2,296 children) were looked after because of their disabilities; the proportion with intellectual disabilities is unknown. Overall, about two thirds of looked after children were in foster placements in 2002; approximately six per cent were placed for adoption; and 12 per cent were in children’s homes. There are also children who attend residential schools on a year round basis, many of whom are still closely linked to their family, with their places paid for by local authorities.

## 2.2 Education

Intellectual disability may be diagnosed at birth; at preschool age; or later in the child’s education. Early intervention services are widely available for preschool children with intellectual disabilities and their families; even children as young as two years old can be offered special education. Recent Government policy has focused on improving the coordination of early intervention services and improving support to families. The “Sure Start Programme” includes a range of initiatives which will improve services for disadvantaged children, including children with intellectual disabilities, and their families (e.g., the extension of home teaching services).

Although recent legislation and Government policy advocates the education of children with special educational needs (SEN) in a mainstream environment, the majority are assessed as having disabilities which are sufficiently severe to warrant education either in special schools (which they can attend from preschool age up to age 19), or special needs units. Typically, inclusive education has only been applied to a few children with mild intellectual disabilities.

The period of compulsory education is nine years, to age 16. In England, Wales and Northern Ireland, the relevant National Curriculum is mandatory for all pupils in state-maintained schools, up to the age of 14. However, SEN pupils can be exempted from the National Curriculum; or the National Curriculum can be adjusted accordingly. Given the National Curriculum’s academic focus, there are different views among self-advocates and education experts, as to its effectiveness for teaching children with intellectual disabilities. However, there is consensus that this group of children must be supported to achieve their academic potential and to acquire vocational skills. In Scotland, curricula are determined at the school level but these must be adapted to the needs of individual pupils. Across the UK, Individualised Educational Programmes (IEPs) must be prepared for pupils with a statement of SEN; these are used as a basis for planning, setting targets and ensuring that pupils make progress.

## 2.3 Transition from education to employment

Despite the existence of various UK organizations which are meant to identify the needs of young people with SEN and ensure the availability of appropriate funding and support transition from further education to real employment is limited. Although some special schools offer work experience and a few have arranged for students to find part-time jobs outside school, most young people with intellectual disabilities leave school with few marketable skills and negligible work experience. The preferred post-school option is a place at a college, either on a special course or in a special unit within the college. However, there is still only limited awareness of the needs of people with intellectual disabilities in further education. Among the barriers are curriculum rigidity, inadequate support staff; and qualification-oriented as opposed to vocation-oriented courses.

On a positive note, there are also some work-based vocational training programmes available for people with SEN, in which young people spend most of their time on placement in a company. The “Entry to Employment (E2E)” programme, in particular, is useful for those with mild intellectual disabilities. There is also a well-developed system of adult education in the UK, and people with intellectual disabilities are able to benefit from the wide range of part-time courses available at adult education centres.

#### 2.4 Access to employment

Government policy advocates the provision of new employment opportunities for people with intellectual disabilities (Department of Health, 2001). However, the majority of people with intellectual disabilities do not access employment. The most recent statement from the Valuing People strategy estimates the number of people with intellectual disabilities in paid employment at only 11 per cent, compared to 49 per cent for people with disabilities in general. Over seventy-five thousand people are estimated to be attending day centres run by local authorities across the UK, which vary considerably in their emphasis on employment preparation. Although exact figures are not available, it can be estimated that around 16,000 people with intellectual disabilities access specialist Government employment programmes for people with disabilities.

In the UK, there are a number of routes for people with disabilities seeking to enter the job market, including via Jobcentre Plus, where all go to seek work and access welfare benefits as job seekers. The UK no longer has a quota system to encourage the employment of people with disabilities. The two main options are mainstream Active Labour Market Programmes (ALMPs) or specialist employment schemes for people with disabilities (e.g., ‘Access to Work’ and ‘WORKSTEP’). Few people with intellectual disabilities access the mainstream programmes, such as “New Deal” and “Work-based Training”. There is greater take-up of specialist schemes provided through central Government, and local authority-run programmes. For example, the WORKSTEP programme offers jobs through a network of supported factories and community placements. In addition, opportunities for work are offered by Remploy Ltd, the biggest Government-funded national provider. The Government also provides help to people seeking open employment through the “Access to Work programme”, which offers financial help with on-the-job support, transport, work aids and workplace adaptations.

Supported employment is one of the most effective ways for people with intellectual disabilities to access employment on the open market. In this model, following an assessment called a vocational profile, individuals are placed in real work settings and allocated a workplace supporter known as a job coach. There are over 400 supported employment agencies operating in the UK. Specialist programmes allow time-limited payments for job ‘coaches’, however, they do not pay for the full model of supported employment. Supported employment agencies are funded largely by local authority social services, despite increasing calls for central Government mainstream funding. Access to supported employment services is uneven across the UK.

#### 2.5 State Benefits

Most people with intellectual disabilities in the UK are reliant on State welfare benefits. The main welfare benefit which people with intellectual disabilities receive is Income Support (IS) which includes a premium for people with disabilities. This is basically a benefit for people who are not in “remunerative work.” Many also receive the Disability Living Allowance (DLA), as well as other non disability-specific benefits. People with intellectual disabilities usually have the status of “economically inactive” and can continue to receive their benefits without regular review. The social welfare system is designed to facilitate the transition from benefits to employment. On moving into full-time employment, loss of benefits such as the IS can be offset by “top-up” benefits, including the Working Tax Credit. Nonetheless, for people with intellectual disabilities in staffed accommodation, the potential loss of Housing Benefit can still act as a disincentive to moving into full-time employment. Usually, for people with intellectual disabilities, the move to part-time employment while retaining benefits is the preferred option. Under the “Supported Permitted Work” rules, people with disabilities can work up to 16 hours a week in supported

work indefinitely, if they receive recognised forms of support. This is a particularly important way for people with intellectual disabilities to join the mainstream workforce, although existing regulations mean that, in practice, they may be even more restricted in the hours they can work, and only receive limited additional income from their work as a result.

### 3 Health Services

Since the establishment of the National Health Service in 1948 health services in the UK have been provided free of charge to all UK citizens. Generally, people with intellectual disability in the UK access health services in the same way as the general population. Access to health services begins with a visit to a 'primary care service' (usually a local doctor known as a general practitioner (GP)). The primary care service is becoming the sole access route to secondary and specialist care for individuals with an intellectual disability (Kerr et al., 1996; Starfield, 1994). The diagnosis of intellectual disability is usually carried out by paediatricians in the health service or associated professionals charged with monitoring the normal development of all children born in the UK, such as general practitioners (GPs) and health visitors. In addition to generic health services there are a few specialist services available to people with intellectual disabilities. For example, there are intellectual disability psychiatric services and epilepsy services.

Recent government policy has outlined four priority target areas for saving lives and improving health: cancer, coronary heart disease and stroke, accidents and mental illness. It emphasised the need to minimise risk factors for ill health associated with personal lifestyles: poor diet, obesity, lack of physical activity, alcohol misuse and smoking (*Saving Lives: Our Healthier Nation*, DoH, 1999).

#### 3.1 The health of adults with intellectual disability

International research has shown that people with intellectual disabilities have repeatedly been found to have untreated morbidity which among other members of the community one would expect to have been identified and resolved (Howells, 1986; Wilson & Haire, 1990; Beange & Bauman, 1991; Webb & Rogers, 1999). They also receive lower levels of health promotion and preventative care, are more vulnerable to certain morbidities and experience higher rates of mortality than the general population (Hollins et al., 1998; Kerr et al., 1996; Leeder & Dominello, 2005; McGuigan et al. 1995; Sutherland et al. 2002; Whitfield et al., 1996).

People with intellectual disabilities experience the same range of health concerns as the general population. However, certain conditions are more common, serious or less well treated, such as epilepsy, sensory impairment, respiratory problems, dental problems, incontinence and being underweight or overweight (e.g., Kendall, 1992a; Springer, 1987; Sutherland et al. 2002; Turner & Moss, 1996; Wood, 1994).

The prevalence of heart disease and cancer have been reported as relatively low in people with intellectual disabilities (e.g., Carter & Jancar, 1983; Cooke, 1997; Welsh Office, 1996). Despite this, several studies have shown that heart disease is a prevalent cause of death in those with mild to severe intellectual disabilities. People with Down's syndrome are at particular risk from heart problems both from their vulnerability to heart defects from birth and from their susceptibility to premature ageing (e.g., Tubman et al., 1991). Occurrence of cancers also varies with age (e.g., Welsh Office, 1996).

Risk of heart disease and cancers, however, may alter as individuals, particularly those with mild intellectual disabilities, live longer, have less restricted lifestyles and exercise greater self-determination to adopt the habits of the general population, such as fatty diets, smoking and the use of alcohol (Holland, 2000; Moss & Turner, 1995; Robertson et al., 2000). In terms of lifestyle health-related risk behaviour, people with intellectual disabilities smoke and use alcohol less than the general population (e.g., Moss & Turner, 1995; Robertson et al., 2000). Moreover, a recent study (Taylor et al., 2004) found no evidence of the prevalence of smoking increasing. However, problems of poor diet, weight and physical inactivity are more prevalent.

Obesity has a range of associated health problems including heart disease, some forms of cancer, hypertension, diabetes and respiratory problems (Bell & Bhate, 1992; Moss & Turner, 1995; Turner & Moss, 1996). People with intellectual disabilities may have more difficulties with maintaining a healthy weight due to additional morbidities such as physical impairments, the side effects of medication, dependence on others to monitor diet and reduced access to information on a healthy lifestyle (e.g., Wood, 1994). The proportions of women with intellectual disabilities found to be obese in several studies (e.g., Emerson, 2005; Robertson et al., 2000; Turner, 1997) are higher than that for women in the UK population generally (Office of National Statistics, 2001). The proportions of men with intellectual disabilities found to be obese are lower than the proportions for women and generally similar to that for all men in the UK population. Apart from gender, obesity has been associated with less severe intellectual impairment (e.g., Robertson et al., 2000) and Down's syndrome (e.g., Robertson et al., 2000).

Less attention has been paid to the health risk of being significantly underweight than to obesity. Being underweight is associated with increased susceptibility to infection and reduced capacity for physical or mental activity or work. Available evidence suggests that significantly higher proportions of men and women with intellectual disabilities in residential services are underweight than their counterparts in the general population (Kennedy et al., 1997; Robertson et al., 2000), with the degree of malnutrition being related to the severity of feeding difficulties people experience. As research has indicated that the polarisation of weight problems, both being over and underweight, is more marked outside of residential services (Wood, 1994), eating a balanced diet is a particularly important general concern. Turner (1997) and Robertson et al. (2000) reported that only a minority of service users with intellectual disabilities ate the recommended proportions of starch, fruit and vegetables, protein and dairy products considered to constitute a healthy, balanced diet. Similar minorities were considered to have poor or fatty diets.

Physical inactivity is a risk factor for cardiovascular disease, some cancers and type 2 diabetes. In the UK, physical inactivity has been defined as participating in moderate or vigorous physical activity less than 12 times in four weeks, a level of inactivity which represents a risk factor for cardiovascular disease (Bennett et al., 1995). By this standard, rates of inactivity found among various groups of adults with intellectual disabilities cluster around 90% (Emerson, 2005; Messent et al., 1998; Turner, 1997), a level comparable to that found in the 75+ age group in the general population. These data are reinforced by the consistency of findings in more general studies of the engagement in activity of people in staffed community housing showing that constructive occupation varies inversely with level of intellectual disability and that people with more severe or profound intellectual disabilities are not effectively supported to take advantage of everyday opportunities for activity (Felce & Emerson, 2004).

People with intellectual disabilities are generally thought to be more likely to experience mental health problems than the general population (Deb et al., 2001; Cooper, 1997; Moss, 1999; Moss et al., 1998). However, diagnosis of psychiatric illness in people with intellectual disabilities is complicated by a number of factors including the possibility of atypical expression and the difficulty of applying classifications dependent on reported internal states to individuals who cannot communicate. Prevalence studies of psychiatric disorders in people with intellectual disabilities report markedly varying rates, (Deb et al., 2001; Hatton, 2002) depending on definitions of disorders, method of case identification, population studied and whether behaviour disorders or behaviourally defined syndromes such as autism are included. The distribution of psychiatric disorders is also different to that found in the general population with lower rates of substance abuse, affective disorders and neurotic disorders but higher rates of psychosis, dementia and autism. Higher levels of dementia, generalised anxiety disorder and depression are found in older populations (Cooper, 1997). Some common mental health problems in the general population, such as depression, may be under-recognised among people with intellectual disabilities as symptoms of lethargy and withdrawal for example may be misconstrued as arising from intellectual impairment. The high rate of prescription of antipsychotic medication, particularly in comparison to the much lower rate of diagnosis of psychosis, has led to concern

that people are being unnecessarily exposed to unpleasant and potentially harmful medication side-effects (Ahmed et al., 2000).

Higher rates of visual and auditory sensory impairment have been found in people with intellectual disabilities than in the general population (e.g., Howells, 1986). People with severe or profound disability are more likely to be affected by visual impairments than non-disabled people and therefore need appropriate screening (McCulloch et al., 1996; Woodhouse et al., 2000). Dual sensory impairment is also more common in people with more severe intellectual disabilities.

Studies of children and adults with intellectual disabilities have suggested that between one fifth and one third of individuals will have active epilepsy, that is to have continued seizures or continued anti-epileptic drug therapy, in comparison to 0.7-1% or less in the general population, with prevalence proportional to the degree of intellectual disability (e.g., Branford et al., 1998; Morgan et al., 2004). Difficulties in the diagnosis of epilepsy have been highlighted, particularly for individuals with communication difficulties unable to express the subjective experience or with movement disorders or stereotyped behaviour which mimic some seizure types (Paul, 1997). Epilepsy is also more complex among people with intellectual disabilities due to the presentation of multiple seizure types and the high severity of epileptic seizures found in individuals, which are resistant to treatment (e.g., Branford et al., 1998; Tobias, 1994). The condition has been found to reduce life expectancy in individuals with all severities of intellectual disability (e.g., Morgan et al., 2001).

UK studies of people with intellectual disabilities have identified respiratory disease as the cause of death in approximately half of cases, compared to about 8% in the general population (Carter & Jancar, 1983; Hollins et al., 1998). Those who are immobile, have additional impairments, have problems with food aspiration or who are underweight are more at risk (e.g., Kennedy et al., 1997).

Studies have shown that people with intellectual disabilities have poor oral hygiene and a high prevalence of gum disease and calculus (e.g., Kendall, 1992b; Shaw et al., 1989). Non-disabled individuals have been found to have better dental hygiene, less gum inflammation, more fillings and fewer extractions, but more untreated caries, than individuals with an intellectual disability (Kendall, 1992a). Adults living in family homes have been found to have significantly more untreated decay and poorer oral hygiene than those living in staffed homes (Filler et al., 2001). Research also indicates that the extent of restorative care can be highly variable and that people with intellectual disabilities are not an homogenous group in this respect (Cumella et al., 2000; Kendall, 1992b). Cumella et al. (2000) comment on the problems of self-report of dental problems and the lack of awareness among carers leading to under-identification. Reluctance to accept treatment, and access, and consent to care are other potentially problematic issues.

### 3.2 Access to primary care

Although people with intellectual disabilities are at higher risk of a range of health problems which result in them having higher health care needs than the general population, they do not access primary health care at a commensurate level (Howells, 1986; Whitfield, Langan, & Russell, 1996; Wilson & Haire, 1990). Community based primary health care teams used by the general population are a responsive rather than proactive service, relying heavily on the ability of the patient to contact and communicate with the general practitioner and other members of the team. However, the adequacy of primary care with respect to people with intellectual disabilities is not just a matter of the frequency of contact befitting the level of health need. The additional and often complex difficulties associated with intellectual impairment mean that the nature of the consultation and the quality of practitioner-led identification of ill-health has also to be adjusted to this population.

Despite the need for enhanced attention to their health, people with intellectual disabilities access primary care no more than the general population (Wilson & Haire, 1990; Whitfield et al., 1996). There may be a number of reasons for this. For example, studies have shown rates of mobility

difficulties among samples of people with intellectual disabilities of 10-18% (Kiernan & Moss, 1990; Lowe & Felce, 1995b; McGrother et al, 1996). Where motor impairment occurs professionals may find it more difficult to perform physical examinations. Challenging behaviour has been found among about 17% of study samples in the UK (DHSS, 1972; Kushlick & Cox, 1973; Qureshi & Alborz, 1992), although the prevalence of behaviour which causes problems for patient examination or treatment cannot be directly inferred. Behaviour is situation specific and individuals who do not usually exhibit challenging behaviour may become extremely distressed during a consultation. In similar vein, patients with a psychiatric illness may also demonstrate challenging behaviour that could obstruct care.

Problems in interpreting a person's behaviour, due to unusual response patterns (Lennox et al., 1997) have been highlighted as sources of difficulty for general practitioners. In addition, Howells (1986), reported that some parents were deterred from visiting the doctor due to embarrassment caused by the behaviour of their adult offspring.

People with intellectual disability are often reliant on their family or carers to identify and communicate their health needs. This reliance has been found to be a major barrier to care. In a study of adults with intellectual disabilities attending a day centre, (Wilson & Haire, 1990) discovered that health problems had been overlooked in instances when carers believed the person to be in good health.

Difficulties with history taking and communication have been highlighted where people with an intellectual disability cannot speak for themselves or are slow at getting information across (Lennox et al., 1997; Kerr, 1998). People with intellectual disabilities may need longer or additional consultations to address certain medical problems (Chambers et al., 1998). Duckworth et al. (1993) investigated the skills involved in interviewing people with intellectual disabilities. They commented that time constraints may force the doctor to ignore the patient in order to elicit information more quickly from a carer. Problems can be exacerbated for patients in residential services if staff turnover results in carers without adequate knowledge accompanying the patient (Lennox et al., 1997), a factor which may be difficult for the doctor to influence unless there is an existing relationship with the staff group. Accurate medical records, however, can reduce many of the difficulties for the doctor caused by unreliable information (Crocker et al., 1987).

In the UK, general practitioners have been reported as feeling a lack of confidence in treating people with intellectual disabilities (Lennox et al., 1997; Stanley, 1998). In a recent study (Stein, 2000), no GP reported feeling totally confident in treating individuals with an intellectual disability, although, 45% said they did some of the time and 49% reported feeling confident most of the time. Lack of confidence is less common among GPs who have had some specialist training (Stanley, 1998). In this regard, GPs have highlighted the usefulness of practical resources such as handbooks, resource guides, lists of specialist physicians, and policy documents on informed consent (Lennox et al., 1997). Two thirds of doctors surveyed in the UK were unaware of the correct procedures for consent to treatment for people with intellectual disabilities, according to English law (Turner et al., 1999).

Primary care teams have been found to lack knowledge of available specialist services and be reluctant to contact them (Bernard & Bates, 1994; Stanley, 1998; Stein, 2000), despite apparently positive attitudes about the value of specialist intellectual disability teams (Kerr et al., 1996).

The additional health needs inherent in people with intellectual disabilities imply a higher level of resource input, if they are to be adequately addressed. Studies have found that patients with intellectual disabilities have higher consultation rates, out of hours visits and contact with specialist services (Eyre, 1996; Stein & Ball, 1999; Morgan et al., 2000). This increased use of services is believed to be even higher for those resettled from long stay institutions where, in some instances, the workload involved was found to be four to five times greater than for non-disabled people (Chambers et al., 1998; Martin & Martin, 2000). People with intellectual

disabilities have also been found to have a higher number of hospital admissions and a greater average length of stay in hospital than the general population (Walsh et al., 1997). McConkey & McAteer (1999) have also argued that care co-ordination is essential to ensure services are delivered in a cost effective manner given the number and range of different professionals typically involved.

### 3.3 Health checks for people with intellectual disabilities

Recent UK intellectual disability policy has highlighted a need for general practice to address the possible deficiency in caring for such a vulnerable population (Learning Disability Advisory Group, 2001; Department of Health, 2001). Such policy has suggested that pro-active health checking may be a means by which the under-identification of treatable morbidity might be addressed. Research has provided some evidence of the utility of health checks in this regard, although their impact in terms of promoting health and quality of life has not, as yet, been fully explored (Martin et al., 1997).

From the late 1990s onwards, the NHS Executive (1998; 1999) began to give good practice guidance to commissioners and providers of health care and to primary care teams about how to address the problem of unmet need for people with intellectual disabilities, while a contemporaneous report (Department of Health, 1999) highlighted the inconsistencies in health service provision across the country, particularly in relation to individuals with severe or multiple impairments, and the lack of clarity in NHS responsibilities. Since then, policy in Great Britain has recommended special arrangements with respect to people with intellectual disabilities in order that their health needs are adequately addressed. In England, the White Paper, *Valuing People*, (Department of Health, 2001) set out specific deadlines for all people with an intellectual disability to be registered with a general practitioner, have a 'health facilitator' and a 'health action plan' In Scotland, *A Partnership for a Better Scotland* (Scottish Executive, 2003) advocated piloting of health screening for people with intellectual disabilities and a subsequent Health Needs Assessment Report, *People with Learning Disabilities in Scotland* (NHS Health Scotland, 2004) recommended the introduction of written anti-discrimination policies at a local level supported by widespread induction training on the needs of people with intellectual disabilities for relevant staff, the provision of required supports to enable equality of access, the development of accessible health promotion responsive to the particular priorities of people with intellectual disabilities, the implementation of health screening and inclusion of health improvement considerations within the 'Single Shared Assessment' developed for each individual. In Wales, advice to the Welsh Assembly Government in the report *Fulfilling the Promises* (Learning Disability Advisory Group, 2001) recommended the provision of accessible information on healthy living to people with intellectual disabilities, the development of an intellectual disability database by each general practice so as to target interventions and health promotion appropriately, the implementation of regular health checks and a system for following up outcome. Subsequent Section 7 guidance issued by the Welsh Assembly Government repeated the need for accessible information and suggested that Local Health Boards might consider enhanced arrangements including the implementation of practice-based registers and regular audited formalised health checks. It also recommended that the multi-disciplinary Unified Assessment process co-ordinated by local authorities should identify and plan for health needs as well as social care needs.

In the absence of an individual being able to request a doctor's care, there is a clear logic to health care being proactive rather than responsive. The need for individuals with intellectual disabilities to have a regular medical examination and general assessment has been articulated by the Royal College of General Practitioners (1990). Although patients with an intellectual disability may fail to report symptoms, conditions can be diagnosed as accurately as for patients in the general population, as long as health professionals use routine diagnostic screenings with a knowledge of risk factors and atypical presentations, in addition to taking account of carer observations (Evenhuis, 1997). Martin et al. (1997) and Baxter et al. (in press) have found annual health checks to be effective in identifying health needs in the UK.

There has been some debate over which group of health professionals should be primarily responsible for conducting health checks: the primary care team, the community learning disability team or indeed carers (Matthews & Hegarty, 1997; Barr et al., 1999; Curtice & Long, 2002). The primary care team has an advantage as the focus for health checking since policy has consistently stressed the importance of including people with intellectual disabilities within generic arrangements and, in any case, the GP is the route via which to access other specialist services. However, despite these rationales, studies have reported a reluctance on the part of general practitioners to perform annual health checks without additional remuneration (Lennox et al., 1997; Stein, 2000; Gill et al., 2002). Moreover, while there are obvious benefits for the health checks to be conducted by the individual's general practitioner; studies have indicated the value of involving nurses in their implementation (Barr et al., 1999; Hunt et al., 2001). In the use of health checks for the elderly, nurses placed a higher value on the use of health assessments and found a higher level of unmet need than general practitioners (Chew et al., 1994; Tremellen, 1992).

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