



## **Equal Treatment: Closing the Gap**

**Background evidence for the DRC's formal investigation  
into health inequalities experienced by people with  
learning disabilities or mental health problems**

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## **1. Introduction**

Opportunities for good health are not shared equally by all people: a wealth of evidence indicates that people in less advantaged circumstances experience poorer health (cf Acheson 1998). The worse health of people with learning disabilities or mental health problems is of particular concern to the DRC, and this paper will review what is known about their health and access to healthcare services. It is important, though, to take account of the wider causes of health inequalities and to assess how these affect people with learning disabilities or mental health problems. The paper will start, therefore, with an overview of these broader issues.

## **2. Socioeconomic inequalities in health: the broader picture<sup>1</sup>**

The chances of living in good health and without impairment are much higher for people in more advantaged circumstances than for those in poverty. The effects of disadvantage are evident from before birth, with a mother's poor nutritional status likely to leave the unborn child under-nourished and vulnerable to serious long-term diseases in adult life (Barker 1998). Differences in birth weight, again associated with socioeconomic gradients, influence subsequent cognitive and physical development and a range of adult diseases. In childhood, there are socioeconomic gradients in growth and height, in language and cognition, as well as in social and emotional adjustment (Kuh et al 2003). As will be noted later, there are also inequalities in children's mental health, with children and adolescents in poorer families more likely to experience mental health problems than those in better-off families (Meltzer et al 2000).

Health inequalities continue in adulthood. Self-rated health - a dimension of health that predicts mortality risk (Wannamethee and Shaper 1991) - is considerably poorer for those in 'routine and

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<sup>1</sup> This section is based on a more detailed paper for this investigation by Professor Hilary Graham (2004).

manual occupations' as compared with those in managerial and professional occupations (Doran et al 2004). This is also the case for long-term illnesses and impairments that limit the performance of everyday tasks (ONS 2002), and for psychological wellbeing (Hemingway et al 1997).

Living with illness and impairment makes economic hardship much harder to avoid. Persisting health difficulties, and the discrimination with which they are associated, increase the risk of unemployment, dependency on welfare benefits and long-term poverty (Maughan et al 1999, Power et al 2002). These risks are not equally shared. Studies suggest that those in higher socioeconomic groups have a better chance of staying in employment in the face of long-term illness and impairment than those in poorer groups (Bartley and Owen 1996, Burstrom et al 2000).

Measures of life expectancy provide some of the clearest evidence of widening inequalities in health. While the health of poorer groups has improved across the last three decades, the rate of improvement has failed to match that achieved by better-off groups. In consequence, the gap between the highest and lowest socioeconomic groups has increased (Roberts and Power 1996, White et al 2003).

Crucially, the evidence suggests that health inequalities cannot be explained by one single set of risk factors, such as smoking or poor diet. Children and adults in poorer circumstances are more exposed to health-damaging environments, including poor housing conditions, work-based hazards, difficult family relationships and stressful life events; they are also more likely to engage in health-damaging behaviours. The mix of health-determining factors varies between health outcomes. For example, the social environment plays a larger role in mental health problems than in, say, accidental injuries, where the physical environment is a key factor.

The NHS has made a major contribution to improving health and has an important part to play in reducing inequalities in behavioural risks and in health. There is evidence, though, that those in higher socioeconomic groups are more likely to benefit from interventions, whether preventive or therapeutic (Acheson 1998, Adams et al 2004, McKee 2002, Reading et al 1994).

### **3. The socioeconomic circumstances of people with mental health problems or learning disabilities**

A review of large-scale studies of mental health problems reported that such problems are more common among people who are unemployed, have fewer educational qualifications, are on a low income, or have a low standard of living (Fryers et al 2003). Estimates from the Labour Force Survey show that 20% of people with mental health problems of working age are in employment, compared with 81% of non-disabled people (DRC 2006). A study of 556 people with mental health problems, carried out by Focus on Mental Health (2001), found that 47% were unemployed, 72% defined themselves as being on a low income, and 66% said they had difficulties making their income last a week. Lewis et al (1998) estimated that 10% of neurotic disorder in the UK could be attributed to a low standard of living. They also reported that standard of living is a more important measure of socioeconomic status than education or social class. Being worse off financially was recognised in the White Paper 'Saving Lives: Our Healthier Nation' (Department of Health 1999a) as being associated with higher rates of mental health problems.

The 1999 ONS survey of the mental health of children and adolescents found, similarly, that lower household income was associated with a greater degree of emotional, behavioural and hyperkinetic problems (Meltzer et al 2000). The highest rate of mental health problems was 22% among boys in families with a gross income of under £100 a week, compared with 7.1% of boys in families with an income of over £770 a week.

Two large-scale studies have reported that families with a child with learning disabilities are significantly economically disadvantaged compared with other families with a child. Analysis of the 1999 ONS study of the mental health of children and adolescents indicated that 44% of families in Great Britain supporting a child with learning disabilities were living in poverty, compared with 30% of other families (Emerson 2003). Analysis of data from the 2001 Family and Children Survey, using a different measure of poverty, indicated that 32% of families in Britain supporting a child with learning disabilities were living in poverty, compared with 24% of other families (Emerson et al 2004). This study reports significantly higher levels of hardship (things gone without) and debt among families supporting a child with learning

disabilities than among other families. Children with learning disabilities also experience more adverse life events, partly accounted for by poverty (Hatton and Emerson 2004). It is likely that the additional financial and social costs associated with bringing up a child with a learning disability will increase the chances of a family descending into poverty and reduce the chances of them escaping from poverty (Emerson 2004).

The recent survey of adults with learning difficulties in England found that 17% of people of working age who have learning disabilities have a paid job (Emerson et al 2005); many of these work part-time and it is likely that many will be receiving benefits as well (Department of Health 2001). A study of people in general households in the US estimated that 30% of adults with learning disabilities (aged 18 and over) lived in households with incomes below the federal poverty level, compared with 11% of other adults (Larson et al 2001).

## **4. Physical health inequalities experienced by people with learning disabilities or mental health problems<sup>2</sup>**

### **4.1 Introduction**

The specific health inequalities experienced by people with learning disabilities or mental health problems have been widely documented. Major reviews have been carried out by the NHS Health Scotland (2004), Alborz et al (2003), Horwitz et al (2000) in the US, Ouellette-Kuntz et al (2004, 2005) in Canada, and the Pomona project in the European Union (Linehan et al 2004) in respect of people with learning disabilities; shorter summaries are increasingly available (e.g. Krahn et al 2006, New Zealand National Advisory Committee on Health and Disability 2003).<sup>3</sup> Much of the evidence in relation to mental health is located in primary research reports, though key issues have been summarised by Cohen and Phelan (2001), Lawrence et al (2001), Phelan et al (2001), Lambert et al (2003), Seymour (2003), Handiside (2004), Samele (2004) and Connolly and Kelly (2005).

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<sup>2</sup> This section summarises the published literature and includes key findings from research commissioned for this investigation.

<sup>3</sup> References to these and other reviews in the text generally relate to studies quoted by the reviews.

Although the evidence indicates differences both within and between the two groups, there are also several points of commonality.

## **4.2 Mortality**

### **4.2.1 People with learning disabilities**

Both adults and children with learning disabilities have an increased risk of early death compared with the general population (Ouellette-Kuntz et al 2004, NHS Health Scotland 2004), though the differences are now diminishing (Linehan et al 2004). One study in the US found that people with learning disabilities died five years earlier than the rest of the population (Janicki et al 1999), while the survival probability for people with learning disabilities in Western Australia was 9 years less for men and 10 years less for women (Bittles et al 2002). Another study in the US reported a mortality rate among young people that was almost three times higher than average (Decoufle and Autry 2002); higher death rates for younger people have also been noted by Durvasula et al (2002) and Patja et al (2001a). In England, Hollins et al (1998) found that, in two districts in London, the risk of dying under the age of 50 between 1982 and 1990 was 58 times higher than in the general population.

Durvasula and colleagues point out that many existing studies are of people in institutions, who are more likely to be older or to have more profound learning disabilities, or register-based populations, which may similarly under-represent people with mild learning disabilities. Whereas Hollins and colleagues found standardised mortality ratios (SMRs) of 9.6 and 18.0 for their two register-based populations (i.e. over 10 and 18 times more deaths than would be expected from general population death rates), Durvasula and colleagues, using a population-based sample in Australia, reported an SMR of 4.9 - though their sample had a maximum age of 50 prior to follow-up. Half of those who died in their study were aged under 35, and these were clustered in the 10-14 age group; the average age at death was 32.

The nature of the learning disability has a clear correlation with early death. Most of those who died under the age of 60 in Durvasula et al's (2002) and Patja et al's (2001) studies had profound learning disabilities. Eyman et al (1990) reported reduced life expectancy for people who were immobile, especially

those requiring tube-feeding, and for older people whose mobility, eating and toileting skills had reduced. In Australia, Bittles et al (2002) noted that the average life expectancies for people with severe, moderate and mild learning disabilities were 58.6, 67.6 and 74.0 years respectively. In Finland, people with mild learning disabilities were found to have a life expectancy that was comparable to the general population (Patja et al 2000), a finding that corresponds with Janicki et al (1999).

The main cause of death for people with learning disabilities is respiratory disease, linked to pneumonia, swallowing and feeding problems and gastro-oesophageal reflux disorder (NHS Health Scotland 2004, Reddihough et al 2001). This is followed by coronary heart disease (CHD), which is increasing as life expectancy improves and more people live in the community; almost half of all people with Down's syndrome have congenital heart problems (Elliott et al 2003). Although overall mortality from cancer is currently similar to the general population, albeit increasing, the pattern is different from the general population, with a higher risk of tumours of the oesophagus, stomach and gallbladder reportedly linked to the higher prevalence of, for example, gallstones and oesophageal reflux (Patja et al 2001b, NHS Health Scotland 2004). Much of the excess mortality experienced by people with learning disabilities is related to associated conditions such as severe mobility impairments, seizures, vision impairments, hearing impairments, and an inability to feed oneself (Ouellette-Kuntz et al 2004). Hollins et al (1998) noted that the risk of death under 50 was significantly associated with cerebral palsy, incontinence, mobility impairments, and residence in hospital. Higher mortality rates for people with Down's syndrome have been linked to the development of early-onset Alzheimer's disease (Strauss and Eyman 1996). Walczak et al (2001) found that having a learning disability was an independent risk factor for sudden unexpected death from epilepsy.

A study in Denmark, based on data up to 1984, reported that preventable mortality was four times higher than in the general population (Dupont and Mortensen 1990). One problem identified in this study related to a reduced ability to communicate physical problems; in addition, accidents in institutions accounted for some of the excess mortality. In the US, Strauss et al (1998a) reported that people in the community were at higher risk of death from

pedestrian accidents, falls, fires and drowning than the general population. Indeed, Strauss et al (1998b) and O'Brien and Zaharia (1998) have found increased mortality for people living in community settings compared to those in institutions. Studies of people with learning disabilities in the USA and Australia have reported increased mortality among members of minority ethnic communities, though the reasons were not explored (Ouellette-Kuntz et al 2004).

A number of factors contribute to these higher mortality rates and the specific causes of differences in morbidity and mortality can be difficult to disentangle: access to treatment is not the only one. Anecdotal evidence refers to physical health problems not being fully investigated by medical practitioners, or infections not being identified by residential home staff, resulting in potentially avoidable deaths (Band 1998, Mencap 2004). The potential danger from unrecognised and untreated health problems has been identified by the National Patient Safety Agency as one of the major causes of health risk (NPSA 2004a).

#### **4.2.2 People with mental health problems**

A wide-ranging review of published research found that people with serious mental health problems were twice as likely to die early as the general population (Harris and Barraclough 1998). Even when deaths from unnatural causes (e.g. suicide) were taken into account, the mortality rate for different groups of people with mental health problems still remained higher. In the case of people with schizophrenia, deaths from natural causes were 1.4 times more than expected, accounting for 62% of the excess deaths: the greatest number of excess deaths was from infectious, respiratory and digestive system disorders, but deaths from endocrine, circulatory, and genito-urinary system disorders also had significantly raised SMRs. A subsequent study found that mortality from natural causes was 2.3 times higher: this related mainly to disease of the circulatory, digestive, endocrine, nervous and respiratory systems (Brown et al 2000). In Sweden, Osby et al (2000) reported SMRs of 2.0 and 1.9 for natural causes of death in men and women with schizophrenia. For people with bipolar disorder, Harris and Barraclough (1998) reported that deaths from natural causes were 1.5 times more than expected: deaths from circulatory and respiratory system disorders had significantly raised SMRs, with circulatory disorders accounting for the greatest number of excess deaths. In Western Australia, Lawrence et al

(2001) found SMRs of between 1.3 and 5.4 for all major natural causes of death among people in contact with mental health services. People discharged from long-term psychiatric care in Scotland between 1977 and 1994 were most likely to die from circulatory problems, with a 50% higher number of deaths than expected; however, the second greatest cause of death, respiratory disease, accounted for four times more deaths than expected (Stark et al 2003). Links between depression and early death from natural causes are also being recognised: depression can, for instance, increase the risk of mortality from CHD (Barth et al 2004). Studies from two states in the USA have shown that the life expectancy of people with schizophrenia or other serious mental illness was around nine years less than for the general population (Dembling et al 1999, Tsuang et al 1980).

Lawrence et al (2001) noted that mortality from cancer was higher than in the rest of the population. And although people with mental health problems had a 30% higher rate of hospitalisation for stroke, mortality was over three times more than expected. This raises the question whether people with mental health problems were receiving the same level of care, relative to clinical need. Druss et al (2001) found that excess mortality among older people with mental health problems who had had a heart attack was accounted for by the poorer quality of medical care, based on five quality indicators. However, premature death may also be associated with late diagnosis (Lawrence et al 2001) or increased intra-abdominal fat in people with schizophrenia (Thakore et al 2002). Nevertheless, Osby et al (2000) suggest that mortality ratios are an important indicator of the quality of psychiatric and medical care, while Lawrence et al (2001) believe that excess mortality could be reduced if people with mental health problems received the same level of care for physical conditions as is given to other people.

Research for this investigation has found that, after adjusting for sex, age at diagnosis, obesity, deprivation and smoking, the risk of mortality for people with CHD, diabetes, stroke and chronic obstructive pulmonary disease (COPD) is between 43% and 77% higher for people with schizophrenia than for those without (Hippisley-Cox et al 2006a). Moreover, people with diabetes who have bipolar disorder have a 50% higher risk of mortality than people without serious mental health problems. Age-adjusted mortality within five years for people with schizophrenia who had

CHD, diabetes, stroke or COPD was higher than for people without serious mental health problems (22%, 19%, 28% and 28%, compared with 8%, 9%, 12% and 15% respectively). For people with bipolar disorder, mortality within five years stood at 15%, 4%, 19% and 24% respectively.

There is also an important association between psychotropic drugs and higher mortality. A number of psychotropic drugs are associated with cardiac side-effects, including some instances of sudden death (Chong et al 2001, Cruchoudet et al 2002, Davidson 2002, Glassman and Bigger 2001, Mehtonen et al 1991, Witchel et al 2003). The effects are particularly likely to be serious where there is coexistent mild heart disease (Witchel et al 2003). Haematologic complications can also occur (Oyesanmi et al 1999). Adverse interactions between general medical and psychotropic drugs are well established (Goldman 2000), both with antipsychotics and for patients on antidepressants (Bingefors et al 1996, Glassman et al 1993). Antidepressant treatment is a statistically significant predictor for increased long-term mortality in older people, notably from cardiovascular causes and even when controlling for pre-existing chronic medical disease (Bingefors et al 1996).

Waddington et al noted in 1998 that the concurrent prescription of more than one antipsychotic was associated with reduced survival. A recent study by Joukamaa et al (2006) found that the relative risk of premature death was increased for each additional antipsychotic drug that was used: although their study only looked at the impact of the older antipsychotics, those drugs remain in common use. Both Joukamaa et al (2006) and Montout et al (2002) raise the question as to whether the increased risk of early death is related to the drugs themselves or to some other characteristics of the patients taking them: further research will be needed to elucidate this. In the meantime, the association with premature death is clear, and such death can be sudden (Lader 1999, Ray et al 2001, Zarate 2001). While the risk is greater for people with a history of cardiovascular and respiratory disease, high doses of antipsychotics have been implicated in the sudden deaths of people in psychiatric units (Pins et al 1993, Thompson 1994).

## 4.3 Morbidity

### 4.3.1 People with learning disabilities

The number of health problems among people with learning disabilities has been estimated to be 2.5 times greater than among other people (van Schrojenstein et al 2000). Several reviews note a higher than average prevalence of a range of medical conditions among both adults and children. In the case of adults, these include epilepsy (25%), hearing and visual impairments (47% and 63% respectively), as well as, for some groups, congenital heart disease, osteoporosis, hypothyroidism, diabetes, respiratory infections, urinary tract infections, and injuries due to falls (Horwitz et al 2000, NHS Health Scotland 2004, Ouellette-Kuntz et al 2004). Research for this investigation found that the rate of respiratory disease was significantly higher (at 20%) than in the remaining population (16%) (Samele et al 2006a). The prevalence of heart disease is higher among people living in community settings than among those living in institutions (Draheim 2006). Women face a comparable risk of cancer to the rest of the population, although the risk is lower for men; however, rates of oesophageal cancer are similar to the general population (Evenhuis et al 1996). There is also increasing evidence of a higher prevalence of *Helicobacter pylori* than in the general population: this can lead to peptic ulcers, gastric cancer and other illnesses, and is a frequent cause of chronic pain unrecognised in people with communication difficulties (Wallace et al 2004).

Prevalence estimates for vision impairments vary widely but indicate a higher prevalence among people with learning disabilities (Owens et al 2006, van Splunder et al 2004). Rates of hearing impairment are higher, particularly among older people, people with Down's syndrome, or people with more profound disabilities (Evenhuis et al 2001, van Schrojenstein et al 1994). The prevalence of mental health problems, too, is higher than in the general population (Linehan et al 2004). Estimates vary considerably, due to difficulties in diagnosis and limitations in research methodologies (Deb et al 2001, Kerker et al 2004). Cooper (1997) suggested that 48% of adults under 65 with a learning disability have a mental health problem, though this included behavioural problems; the rate among people aged 65 or over was 69%. Others suggest a prevalence of 50% among people with more profound impairments, and 20-25% among people with mild learning disabilities (New Zealand National

Advisory Committee on Health and Disability 2003). A number of studies have found high rates of oral health problems (Linehan et al 2004, Owens et al 2006). Dental disease is twice as common as in the rest of the population, with higher levels of both tooth decay and gum disease (Cumella et al 2000, Scott et al 1998). People with Down's syndrome who have Alzheimer's are more likely to experience a range of health problems, compared to those without Alzheimer's (McCarron et al 2005).

As in the case of people with mental health problems, neuroleptic medication and polypharmacy can result in serious complications: these include increased confusion, constipation, postural instability, falls, incontinence, weight gain, changes to hormones and body chemistry, and movement disorders (Ouellette-Kuntz et al 2004). Studies have estimated that between 20% and 66% of people with learning disabilities are given psychotropic medication, principally antipsychotics (Linehan et al 2004). However, it is often used as a form of chemical restraint for the social control of troublesome behaviours rather than to treat mental health problems (Ahmed et al 2000, Holden and Gitlesen 2004, Linehan et al 2004, Matson et al 2000, Stolker et al 2002). Its effectiveness in addressing challenging behaviour is questionable (Brylewski and Duggan 1998) and there are strong arguments for stopping or reducing its use for many people (Ahmed et al 2000).

#### **4.3.2 People with mental health problems**

People with mental health problems have higher than average rates of physical illness (Seymour 2003). A study in Wales found that the reported prevalence of specific physical conditions was generally at least twice as high for people with serious mental health problems as for other people (Richards et al 2005). It is likely that physical illness can cause or exacerbate mental health problems (Lambert et al 2003), and worse physical health is already evident in people who present for the first time with psychosis (Samele et al 2003). The process also works the other way round, with worse mental health having an adverse effect on physical health (Hotopf et al 1998, Shift 2004). In the case of depression, the coexistence of physical illness worsens the prognosis of both (Wells et al 1989).

One of the main physical health problems experienced by people with mental health problems is cardiovascular disease (Davidson 2002, Lambert et al 2003, Lawrence et al 2001, Kendrick 1996,

Ryan and Thakore 2002). People with schizophrenia or bipolar disorder are 1.6 times more likely to develop ischaemic heart disease, 1.9 times more likely to have a stroke, and 1.3 times more likely to have hypertension (Hippisley-Cox and Pringle 2005). The links with smoking and obesity are well-known. In addition, major weight gain induced by antipsychotics is well established and represents a serious concern (Allison et al 1999b, Elmslie et al 2000, Taylor and McAskill 2000). There is also an association between depression and an increased risk of heart disease (Rugulies 2002, van Melle et al 2004). People with depression are 1.6 times more likely to have ischaemic heart disease and 1.8 times more likely to have a stroke (Samele et al 2006a). Antidepressants themselves represent a risk factor for heart disease (Glassman et al 1993, Hippisley-Cox et al 2001). Stimulant drugs to treat attention-deficit hyperactivity disorder (ADHD) also carry cardiovascular risks (Nissen 2006).

Between 15 and 18 per cent of people with schizophrenia are likely to have diabetes - this is between two and four times higher than in the general population (Schizophrenia and Diabetes Expert Group 2004); research for this investigation reported 2.8 higher prevalence (Hippisley-Cox and Pringle 2005). For people with bipolar disorder, prevalence is generally between two and three times higher (Schizophrenia and Diabetes Expert Group 2004) - 1.8 times higher according to Hippisley-Cox and Pringle (2005). Although the development of atypical antipsychotic drugs was believed to be linked to the development and exacerbation of diabetes (Henderson and Ettinger 2003), this is now being questioned (Bushe and Leonard 2004, Haddad 2004, Marder et al 2004). It remains the case, though, that atypical antipsychotics are associated with impaired glucose metabolism, even if the specific causal routes are still not known and pre-existing risk factors may be involved (Bushe and Holt 2004, Cavazzoni et al 2005, Schizophrenia and Diabetes Expert Group 2004). One study in the US found that diabetes control was generally poor, though better among people with schizophrenia than among people without serious mental health problems (Dixon et al 2004).

Respiratory disease, too, is more common in people with mental health problems. International data indicate that a diagnosis of emphysema or chronic obstructive pulmonary disease (COPD) is nearly twice as likely for people with schizophrenia (Chafetz et al 2005), with hospital treatment also more common (Lawrence et al

2001). Data from England and Wales for this investigation show that people with schizophrenia or bipolar disorder have a 1.4 higher prevalence of COPD, while the rate for people with depression is 1.6 higher (Samele et al 2006a). The risk of cancer has generally been found to be similar to or higher than in the rest of the population (Lawrence et al 2001, Lichterman et al 2001). In analysis for this investigation, Hippisley-Cox et al (2006b) found that, after adjustment for deprivation, smoking status, obesity and use of medication, people with schizophrenia are 90% more likely to develop colorectal cancer, the second most common cause of cancer death in Britain, while women with schizophrenia are 42% more likely to develop breast cancer. Hepatitis B and C are more common in people with mental health problems, as is HIV/AIDS (Lambert et al 2003, Lawrence et al 2001). There is also a higher prevalence of sexually transmitted diseases (Coverdale et al 1997, Lawrence et al 2001). Not least, oral health is often poor, with caries, inflammation of the gums and oral plaque being common (Mirza et al 2001).

People with schizophrenia are also younger when serious physical ill-health is diagnosed. Of those who develop CHD, 31% are diagnosed under the age of 55, while the rates for diabetes, stroke and COPD are 41%, 21% and 23%; the comparable rates for people without serious mental health problems are 18%, 30%, 11% and 17% respectively (Hippisley-Cox et al 2006a).

Antipsychotic medication has a number of additional adverse effects on health. It can lead to heart problems, low blood pressure, lipid abnormalities (relating to fats in the blood), interference with neurotransmitters, excess production of prolactin (hormone linked to breast milk production and fertility), cataract formation, bone marrow disorders, osteoporosis, seizures, extrapyramidal symptoms such as motor restlessness and parkinsonism, and tardive dyskinesia (involuntary movement disorders and a precursor of senile dementia) (Collaborative Working Group on Clinical Trial Evaluations 1998, European Commission (undated), Hennessy et al 2002, Lader 1999, Marder et al 2004, Novartis 2005, Scanlan and Houltram (undated), Wirshing et al 2003). There are also small but significant links with breast and endometrial cancer (Wang et al 2002, Yamazawa et al 2003).

The NICE (2002) guidance on schizophrenia states that doctors should discuss the benefits and side-effects of medication before it is prescribed. Moreover, comprehensive health checks are needed before an antipsychotic is prescribed (Lader 1999). Regular monitoring is essential and alternative therapy should be prescribed if the side-effects are serious and/or persistent (Lader 1999). In practice, however, many people are not told about possible side-effects (SANE 2005). A survey of 100 psychiatrists found that 10% did not proactively discuss long-term health risks (Sane 2005), while qualitative research has highlighted a dilemma for psychiatrists in balancing a concern with side-effects against a wish to ensure mental health problems are addressed, with the end result that many are 'economical with the truth' (Seale et al 2006: 2866). The same study noted that psychiatrists sometimes have to take people off multiple medications that have been prescribed in primary care. It is essential, therefore, to review medication and its side-effects. However, one study found that only half of a sample of 164 people with mental health problems who already had known physical health problems had received reviews of their medication and its side-effects (Richards et al 2005). In the case of people with dementia, the prescribing of antipsychotic medication to control behaviour may be inappropriate in the first place, and occurs despite the availability of good practice guidelines (Fossey et al 2006, Howard et al 2001).

Although many people wish to come off psychotropic medication, the extent of support from doctors is variable and people may stop taking medication without telling their doctor (Coldham 2003, Read 2005). The benefits of coming off can include better mental ability and feeling more alive, as well as no longer experiencing the adverse effects (Read 2005). However, this has to be balanced against control of mental health problems.

#### **4.4 Unrecognised needs of people with learning disabilities**

Although people with learning disabilities have a greater variety of healthcare needs compared with the general population (US Department of Health and Human Services 2001), many of their needs are unrecognised and unmet (Kerr 2004, NHS Health Scotland 2004). Assessments in a number of countries, including England and Wales (Howells 1986, Wilson and Haire 1990), have identified high rates of previously unrecognised or poorly managed medical conditions, including hypertension, obesity, heart disease, abdominal pain, respiratory disease, cancer, gastrointestinal

disorder, diabetes, chronic urinary tract infections, oral disease, musculoskeletal conditions and osteoporosis, thyroid disease, and visual and hearing impairments (Ouellette-Kuntz et al 2004). Consultation rates have been variously found to be similar (Elliott et al 2003), higher (Kerr 1998) or lower (National Patient Safety Agency 2004a) than the general population, yet high levels of unmet need remain, commonly found conditions may not be addressed and health prevention not provided (Horwitz et al 2000). Given the higher rates of ill-health, even similar levels of consultations suggest an under-use of primary care. One study reported that three-quarters of people with learning disabilities who received assessments needed follow-up interventions (Ouellette-Kuntz et al 2004). Those interventions reflect the findings of numerous other studies in highlighting unmet needs for:

- health protection, involving vaccination, regular checks for existing conditions and smoking cessation;
- referral to an optician;
- haematological testing, medication levels, cholesterol, blood sugars and hepatitis testing;
- weight, obesity or underweight management;
- ENT services, including hearing tests;
- gynaecological and other women's health concerns (Ouellette-Kuntz et al 2004).

The low proportions of women with learning disabilities who receive cervical and breast screening has been much discussed, with less than 20% take-up of cervical screening frequently reported (Djuretic et al 1999, Whitmore 1999, Pearson et al 1998, Stein and Allan 1999). Broughton and Thomson (2000) reported that 40% of 52 women had received a smear test, but the sample did not include women with more profound disabilities.

Unpublished data from the English national survey of adults with learning difficulties indicate that 33% of eligible women reported having had a cervical smear (Emerson, private communication). Analysis for this investigation found that 13% of eligible women in Wales received cervical cytology (Kerr et al 2005) but a separate study in four areas of England and Wales reported a rate of 47% (Samele et al 2006a); the reasons for the variation between these and other studies are not known. However, the take-up rate in England as a whole is 80% (NHS Cancer Screening Programmes 2005a). Broughton and Thomson (2000) noted that having a smear test was correlated with being sexually active, having had

more than one sexual partner, having been pregnant, and a past history of smoking, though numbers in all instances were small. They also noted that women often experienced pain and difficulty with the procedure. Individual support and counselling may, however, only increase take-up by a small amount. Biswas et al (2005) reported that such intensive input resulted in an increase from 16% to 22%, but they judged that there were appropriate reasons for non-take-up by 60%. This corresponds with the findings of Rogg et al (2003), who found that only three additional women had a smear test, out of 25 who had not previously had one; again, the reasons for non-take-up by the remaining 22 were considered to be appropriate.

Take-up of breast screening is higher, and has been considered to average at around a third (Linehan et al 2004). Piachaud and Rohde (1999) reported 10% and Davies and Duff (2001) 52%, albeit based on very small numbers in each case. Davies and Duff also noted that only 58% of eligible women had received invitations. The English national survey found that 58% of eligible women reported having their breasts checked, though this may not equate with mammography (Emerson, private communication). Across the UK as a whole, take-up runs at 75% (NHS Cancer Screening Programmes 2005b).

Levels of immunisation against tetanus, poliomyelitis and influenza are all lower than in the general population (NHS Health Scotland, 2004). Influenza immunisation is particularly important, given the high prevalence of respiratory infections and premature deaths from pneumonia.

## **4.5 Lifestyle issues**

### **4.5.1 People with learning disabilities**

Although prevalence rates vary widely, the literature reports wide agreement on the increased prevalence of obesity and overweight among people with learning disabilities (Linehan et al 2004). Estimates of prevalence range up to 51% for adults (Horwitz et al 2000, Linehan et al 2004, Merriman et al 2005), with at least some of the disparities accounted for by differences between countries, dates of studies, and the characteristics of the samples (Jansen et al 2004, Linehan et al 2004, Rimmer and Yamaki 2006). Two recent studies of people in contact with primary care services in England and Wales reported rates of 28% and 35%, with the rate

for women being 40% in both studies (Kerr et al 2005, Samele et al 2006a). The high rate for women corresponds with data from other studies, which also show high rates for people living in more independent settings in the community (Messent and Cooke 1998, Prasher 1995, Rimmer et al 1995, Robertson et al 2000). Although the nature of some learning disabilities is associated with increased weight, a poor diet and low levels of physical activity are major contributory factors (Robertson et al 2000, Stanish et al 2006). Having limited opportunities to influence what they eat, especially if shopping and cooking are done by others, may mean little control over diet (Rodgers 1998). However, poor diet has also been associated with less profound disabilities and more independent living arrangements (Robertson et al 2000). In addition, physical activity levels may be low. This is mainly the case for people with more severe disabilities (Robertson et al 2000), though a study in the USA found that people in group homes exercise less than those living in institutions or with their families (Rimmer et al 1995). One study found that 92% of people with mild or moderate difficulties undertook less than the minimum recommended amount of physical activity (Messent and Cooke 1998); the English National Survey of Adults with Learning Difficulties reported that 46% of respondents said they did some exercise that made them out of breath and sweaty, and 15% said they did so at least three times a week (Emerson et al 2005). Barriers to physical activity include difficulties in accessing exercise and leisure facilities, a reliance on others for transport, lack of support staff, low financial resources, unclear policy guidelines for day and residential services, a lack of motivation, and overprotectiveness by carers (Chapman et al 2005, Messent and Cooke 1998).

Smoking rates among people with mild learning disabilities have been reported to be comparable to those in the general population (Rimmer et al 1995), or even higher (Tracy and Hosken 1997). A survey in England found that 12% of people living in dispersed housing smoked, with far fewer in residential campuses or village communities (Robertson et al 2000). Samele et al (2006a) reported that 15% of those identified on primary care databases as having learning disabilities were current smokers. The English National Survey noted that 19% of respondents said they were current smokers (Emerson et al 2005).

The sexual health needs of people with learning disabilities have been largely overlooked (NHS Health Scotland 2004). Results of research studies show little consistency, though it appears that people with people with mild learning disabilities have similar rates of sexual activity to those in the general population, while people with moderate or severe disabilities have less (McCabe 1999, McGillivray 1999, Servais 2006). However, not all such activity is consensual: 13% of the women in one study had been subjected to sexual abuse (Chamberlain et al 1984). The risk of sexually transmitted diseases is a real one and supportive information and services are needed (Ailey et al 2003, Servais 2006).

Analysis of general practice data for this investigation found that people with learning disabilities who did not have a previously identified health problem were less likely to receive general tests for blood pressure, cholesterol, urine analysis and weight (Samele et al 2006a). However, obese or overweight people received a similar amount of dietary advice to that given to other obese or overweight people. An effectiveness review of interventions to improve the physical health of people with learning disabilities noted that health can be improved through appropriate weight and fitness programmes (Alborz et al 2006).

#### **4.5.2 People with mental health problems**

For people with mental health problems, high levels of smoking, obesity and a lack of exercise all contribute to ill-health and potentially lead to avoidable death (Brown et al 2000, Friedli and Dardis 2002, Phelan et al 2001, Richards et al 2005, Ryan and Thakore 2002). Smoking rates are high (Corvin et al 2001, Glassman et al 1990, Goff et al 1992). Analysis of the national survey of psychiatric morbidity in Britain found that 64% of people with probable psychosis were current smokers, as compared with 29% of people without psychosis; and 44% of people with significant levels of neurotic symptoms were current smokers, compared with 27% of those without significant neurotic symptoms (Coulthard et al 2002). Two other studies in the UK reported current smoking rates of 50% and 70% among people with serious mental health problems and people with schizophrenia respectively (Smith et al forthcoming, McCreadie 2003). Hippisley-Cox and Pringle (2005), using a general practice database on 1.7 million people, found that 61% of people with schizophrenia had a recent history of smoking (among those whose smoking status

was recorded), compared with 46% of people with bipolar disorder and 33% in the rest of the population.

There is some debate about whether smoking is a cause or effect of mental health problems (Breslau et al 1998). One study found that 90% of people had started smoking before their illness began (Kelly and McCreadie 1999). However, some psychotropic medication is associated with an increase in smoking (Goff et al 1992). Smoking can also lead to higher doses of medication being prescribed (ibid). There are some suggestions that it may cause depression, or that the environment or genes may predispose to both smoking and depression (ASH 2004, Kendler et al 1993). Smoking can help to alleviate some schizophrenic symptoms or depression, and can thus represent a form of self-medication; a reduction of smoking can lead to an increase of depression, making cessation more difficult (Glassman et al 1990).

Although obesity is an issue for people with schizophrenia even before antipsychotics are taken into account, antipsychotics themselves result in major weight gain (Allison et al 1999a, 1999b, Catapano and Castle 2004, Taylor and McAskill 2000), with a consequent potentially serious impact on appearance and morale as well as on health (Dean et al 2001). Studies have estimated obesity among people living in institutions as well as in community settings in a range of countries and have estimated prevalence at between 30% and 60% for people with psychotic conditions, up to three times higher as in the general population (Allison et al 1999b, Coodin 2001, Dickerson et al 2006, McCreadie 2003, Smith et al forthcoming, Taylor and McAskill 2000). A review of obesity among people with bipolar disorder found a higher risk of obesity than in the general population (Keck and McElroy 2003), with Fagiolini et al (2003) estimating prevalence at 35% in a US sample, compared with 20% generally. Recent analysis for this investigation, based on data held in general practices in England and Wales and relating to people living in the community, found that, of those whose body mass index (BMI) is recorded, 33% of people with schizophrenia and 30% of those with bipolar disorder are obese, compared with 21% in the rest of the population (Hippisley-Cox and Pringle 2005). The diet of people with serious mental health problems falls below acceptable levels and has been found to be poorer than that of the general population and of the socioeconomic group with the poorest diet (McCreadie 2003, Smith et al forthcoming).

The need for effective health promotion advice and support is clearly indicated. Yet, although consultation rates with general practitioners (GPs) are 3 to 4 times higher than for the general population (Seymour 2003), some studies have found that people who use psychiatric services are less likely to be offered health promotion interventions such as smoking cessation, blood pressure checks or prescriptions for leisure (Brown et al 1999, Burns and Cohen 1998, Cohen and Hove 2001, Friedli and Dardis 2002). Research for this investigation found that the level of general tests (such as blood pressure, cholesterol, urine analysis and weight) for people with serious mental health problems was often higher than for the rest of the population (Samele et al 2006a). However, a survey of over 200 GPs from across the UK reported that only around half say they provide advice on healthy eating, weight management or exercise to people with serious mental health problems (Rethink 2005b). Steptoe et al (1999) note that health promotion involves more than the provision of simple information and advice, but found that GPs and practice nurses lack confidence in lifestyle counselling skills.

A review of the literature on smoking and mental health suggests that some of the excess mortality of people with mental health problems is potentially preventable if they had support to stop smoking (McNeill 2001). National guidelines on smoking cessation include both the prescription of pharmacotherapy and referrals to intensive support services (NICE 2006). Hippisley-Cox and Pringle (2005) reported that smoking cessation advice is more common for smokers with serious mental health problems than for other smokers (65% and 59% respectively). The level of prescriptions for smoking cessation treatments is also higher (10%, compared with 8%), though low in absolute terms. People with mental health problems are likely to have limited incomes and be more reliant on such prescriptions, rather than being able to purchase over-the-counter remedies. Although effective treatments to help people stop smoking do exist (Samele et al 2006b), they are thus not routinely offered to people with mental health problems, even though they may wish to quit (McNeill 2001). Kelly and McCreadie (2000) note that smoking cessation rates among people with mental health problems are often low; however, the common perception that cessation support will be unsuccessful is inherently discriminatory.

People with serious mental health problems also engage in less physical activity than others (Richards et al 2005, Richardson et al 2005). Limited finances mean that access to leisure and exercise may itself be limited; this is compounded for people without easy access to transport, especially in rural areas (Dean et al 2001). Exercise referral schemes are now widespread, but only 15% of GPs who have access to such schemes in the UK say they use them 'fairly frequently' for people with mild or moderate depression, despite their potential benefits (Mental Health Foundation 2005).

The level of dietary advice given to people with schizophrenia or bipolar disorder who are obese or overweight has been found to be similar to that for other people (Samele et al 2006a). However, obese or overweight people with depression are given less. A review of the effectiveness of interventions to improve physical health, carried out for this investigation, noted that reductions in weight can be gained for people with schizophrenia through pharmacological, behavioural and dietary interventions (Samele et al 2006b).

A further lifestyle issue concerns sexually transmitted disease. This is a particularly high risk for people with mental health problems, given its association with multiple and sometimes high-risk sexual partners and high rates of coerced sex (Coverdale et al 1997, Dickerson et al 2004, Gray et al 2002, Miller 1997). Policy reports on mental health seldom refer to sexual health promotion and people with mental health problems are under-targeted in HIV prevention programmes (Gray et al 2002, Sherr 1998). However, Gray et al (2002) argue that people with schizophrenia should be considered an at risk population for HIV infection and other sexually transmitted diseases.

#### **4.6 Causes of inequalities**

The causes of ill-health are many and varied. It is crucial to distinguish those factors that underpin the poorer health of people with learning disabilities or mental health problems from the poorer healthcare they may also receive - though both should be considered open to change and health improvement.

As was discussed earlier, poor health is linked to poor socioeconomic circumstances (Acheson 1998, Banks et al 2006, Graham 2004), and people with learning disabilities or mental

health problems are particularly likely to live in poverty (see section 3). Their health is thus already compromised by their poor circumstances. No account of health inequalities can ignore this; however, other factors also need to be recognised.

For some people with learning disabilities, mortality and morbidity are related to their impairments: obesity and heart disease, for instance, are associated with some genetic causes of learning disabilities, and people with Down's syndrome have increased risks of hypothyroidism and early onset dementia (Howells 1986, NHS Health Scotland 2004). Mobility impairments can mean that physical exercise is difficult.

People may not access services for a range of reasons (Alborz et al 2005, NHS Health Scotland 2004). Symptoms of health problems may not be recognised (Jeste 1996). People may not tell others about possible illness (Keywood et al 1999) and symptoms may be presented late, once a problem has set in and its effects are more damaging. Expectations of healthcare services may be low, whether due to difficulties in making decisions about when to seek help, previous poor experiences, or fear of the consequences (Alborz et al 2003, Horwitz et al 2000). Invitations to attend checks may not be taken up: Werneke et al (2006) found, for instance, that women with more serious psychosis were less likely to attend breast screening clinics. Family members or professional carers may be unaware of problems, or may decide that the nature of those problems does not warrant making contact. This may be exacerbated by additional problems such as having to wait in a waiting-room for a length of time (Alborz et al 2003, Band 1998, Homeless Link Cymru 2006). Physical access barriers, including poor signs and a lack of communication aids such as induction loops, add to the difficulties (Alborz et al 2005). Deaf people, two in five of whom experience a mental health problem during their lives, experience considerable barriers in accessing services (du Feu 2003, Sign and Mental Health Foundation (undated)).

Not least, some people are not registered with GPs in the first place (Cohen and Phelan 2001, Department of Health 2001). This is a particular issue for people with mental health problems, with many reports of people being struck off GPs' lists and difficulties re-registering (Buntwal et al 1999, Moore 1999, Read and Baker 1996). Buntwal et al (1999) noted that 30% of people with mental

health problems using one mental health unit had been struck off GPs' lists at some point; there is also evidence that 14% of de-registered patients were struck off more than once (Public Administration Select Committee 1999). Permanent registration is particularly difficult for refugees, asylum seekers and homeless people (Homeless Link Cymru 2006, MIND 2004). Pleace et al (1999) report on confusion over the rights of rough sleepers to permanent registration, with some practices believing this requires a permanent address. They point out that the absence of permanent registration potentially undermines the quality and continuity of care. Registration appears to be less of a problem for people with learning disabilities (Alborz et al 2003), though reports exist of individual people with autistic spectrum disorders being struck off lists (Taylor 2003). One of the action points in the English White Paper 'Valuing People' (Department of Health 2001) was that all people with a learning disability should be registered with a GP by June 2004.

Other problems arise once contact has been made with a healthcare professional, and those problems can be either patient-based or doctor-based (Baxter and Kerr 2002, Lennox et al 1997). Communication problems may mean that symptoms are presented in terms which professional staff find hard to understand (Lennox et al 1997, National Patient Safety Agency 2004b); conversely, professionals may assume that people understand more than they do (Alborz et al 2003). Although some doctors complain of patients' lack of compliance with management plans (Lennox et al 1997), evidence received for this investigation suggests that patients may be given insufficient information about those plans, such as the need to continue taking prescribed medication. In other instances, a greater acceptance of doctors' opinions than may be the case in the general population, together with the practical difficulties involved in attending a surgery, can lead to less persistence in obtaining satisfactory outcomes: the NHS Health Scotland report (2004) quotes the example of a person with a cough being offered reassurance at a first appointment, antibiotics the next time, and a chest X-ray on the third occasion; it asks whether a person with a learning disability would persist to this extent.

Although many people with learning disabilities or mental health problems, including the carers of children, speak highly of the general healthcare they have received (cf. Beecroft et al 2001,

National Patient Safety Agency 2004c, Rutter and Seyman 1999, Singh 1997), others have referred to inappropriate stereotypes, negative attitudes by reception staff or clinical staff, and negative assumptions about a person's quality of life (Band 1998, Cohen and Phelan 2001, Friedli and Dardis 2002, Gill et al 2002, Keywood et al 1999, Mencap 2004, NHS Health Scotland 2004, Royal College of Psychiatrists 2001).

While attitudes may not always be associated with poorer outcomes (Kerr 1998), they do affect the extent to which concerns are treated seriously or dismissed (Alborz et al 2003, Ouellette-Kuntz et al 2004), symptoms are explored (Mencap 2004, Read and Baker 1996), and opportunities to carry out screening or medicine reviews are taken up or missed (Alborz et al 2003). Diagnostic overshadowing is frequently reported, with physical or psychological symptoms being inappropriately attributed to the learning disability, mental health problem or, indeed, age (Band 1998, Coldham 2003, NHS Health Scotland 2004, Ouellette-Kuntz et al 2004, Read and Baker 1996, Rutter and Seyman 1999, Shift 2004, Thornicroft 2006). Unfounded assumptions about lifestyles can underlie GPs' withdrawal of women with learning disabilities from cervical screening programmes (NHS Health Scotland 2004). The palliative care needs of people with dementia are not always appropriately met (Lloyd-Williams 1996).

The National Patient Safety Agency (2004b) noted that implicit discrimination towards infants with Down's syndrome, in particular, makes it imperative to monitor deep-seated prejudices and assumptions about the worth of people with learning disabilities and the quality of their lives. Treatments are sometimes denied on the basis of a person's learning disability or mental health problem. Evidence from the USA and Australia in relation to secondary care indicates that people with mental health problems who had had heart attacks were less likely to receive angioplasty or coronary artery bypass grafts and that rates of cardiac revascularisation are lower, despite higher rates of heart disease (Druss et al 2000, Lawrence et al 2001). In Western Australia, people with schizophrenia had a much lower rate of cardiovascular procedures, despite having among the highest rates of smoking and obesity (Lawrence et al 2001). In the UK, questions have been raised about the availability of heart surgery for people with Down's syndrome (Royal Brompton Hospital 2001, Rutter and

Seyman 1999) and organ transplants for people with schizophrenia (Byrne 2000, Masterton 2000).

Values and attitudes may sometimes be of less influence than limited knowledge, confidence and background information (Williamson et al 2004). Many studies refer to GPs' and nurses' lack of specialist knowledge about learning disabilities (including autistic spectrum disorders), lack of training on medical and nursing courses, poor communication skills with people with learning disabilities, feelings of inexperience, and the lack of attention to learning disability in general practice journals (Baxter and Kerr 2002, Lennox and Kerr 1997, Lennox et al 1997, Linehan et al 2004, Martin 2005, Melville 2005, NAS 2003, Williamson et al 2004).

Good communication and a more proactive approach require more time for consultations and a better understanding of the needs of people with learning disabilities or mental health problems (Baxter and Kerr 2002, Lennox et al 1997). People should be enabled to make decisions about their health themselves, instead of others doing so on their behalf (Keywood et al 1999). Communication is needed in appropriate forms, not relying on a person's ability to read appointment letters, information leaflets and consent forms (Alborz et al 2003, NHS Health Scotland 2004). Training to identify and meet needs is also indicated (Cohen and Phelan 2001, Linehan et al 2004, Seymour 2003, Singh 1997, Stein 2000). However, GPs do not all appear prepared to play a more active health role, for instance through annual health checks or regular vision or auditory testing (Kerr 1998). Some do not see themselves as the most appropriate professionals to provide health care for people with learning disabilities (Hogg 2001). On the other hand, members of community learning disability or mental health teams are less able to identify and manage physical health problems (Alborz et al 2003, Phelan et al 2001, Wright et al 2006).

Analysis for this investigation has revealed evidence of inconsistencies in the way problems are identified or managed within primary care. On the positive side, people with schizophrenia and bipolar disorder do not, for example, experience any difference in investigations following postmenopausal or rectal bleeding, both of which can be symptoms of cancer as well as of non-malignant conditions (Parker et al 2006). After adjusting for

age, sex and deprivation, people with serious mental health problems and COPD have similar rates of forced expiratory volume (FEV1) and inhaler technique checks as other people with COPD (Hippisley-Cox et al 2006c). Unadjusted levels of blood pressure recording are higher for people with schizophrenia than in the remaining population (60%, compared with 44%) (Hippisley-Cox and Pringle 2005).

However, people with schizophrenia are less likely to have a diagnosis of COPD confirmed by spirometry (72%, compared with 83% for people without schizophrenia, after adjusting for age, sex and deprivation) (Hippisley-Cox et al 2006c). People with schizophrenia and heart disease have fewer blood pressure or recent cholesterol tests than others (86% and 68%, compared with 92% and 80%) (Hippisley-Cox and Pringle 2005). People with schizophrenia who have had a stroke have fewer cholesterol tests than other people with a stroke (48%, compared with 63%) and lower rates of aspirin use (63% and 68% respectively) (Hippisley-Cox and Pringle 2005). People with schizophrenia and CHD are less likely to have had a recent cholesterol test than other people with CHD (88%, compared with 95%, after adjusting for age, sex, deprivation and co-morbidity); and 66% of people with schizophrenia who have CHD are likely to be prescribed statins to reduce lipids, compared with 81% in the case of other people with CHD (Hippisley-Cox et al 2006d). People with learning disabilities who have diabetes have fewer BMI measurements than other people with diabetes (78%, compared with 95%), and those with a stroke have fewer blood pressure checks than others with a stroke (78%, compared with 99%) (Samele et al 2006a).

## **4.7 Experiences of specific groups of people**

### **4.7.1 People from Black and Minority Ethnic (BME) communities**

People from some BME communities experience worse health than the general population (HSCIC 2005). Diabetes is over twice as common among Afro-Caribbean and South Asian people, while rates of angina, heart attacks and stroke are also higher among South Asians. Although the use of primary care by South Asians is high (Balarajan et al 1989, Gillam et al 1989, Scaife et al 2000), this does not mean that services are always appropriate or of sufficient quality (Rhodes et al 2003). Linguistic and cultural barriers, time constraints and a lack of understanding of

individuals' health beliefs all make communication and effective treatment more difficult to achieve (BME Health Forum and Migrant & Refugee Communities' Forum 2005, Mir 2003).

The prevalence of both depression and psychosis is higher among Afro-Caribbeans than among Whites (Nazroo 1998). Depression and psychosis are as common among Asian people who have been educated in Great Britain as among Whites; for other Asian people, lower reported rates may be due to problems of identification or diagnosis (Nazroo 1998). More recent evidence indicates that non-psychotic mental health problems are more common among Pakistani men aged 35-54 and Indian and Pakistani women aged 55-74 (Weich et al 2004). Despite the higher prevalence of depression in some groups, identification and treatment rates are lower (Nazroo 1998, Wilson and MacCarthy 1994).

The use of primary care services by Afro-Caribbean people with mental health problems is low. Keating et al (2002) refer to 'circles of fear', whereby service staff see Black people with mental health problems as potentially dangerous, fail to treat them with respect, and rely on medication rather than talking therapies. Black people then see services as unhelpful or even harmful, which stops them from using those services. Use of services only in crises reinforces the circles of fear. Several reports have highlighted the over-representation of Black people in acute care and noted that Black people are more likely to access mental health services through the criminal justice system or be compulsorily detained under the Mental Health Act (Bhugra et al 2004, BME Health Forum and Migrant & Refugee Communities' Forum 2005, Healthcare Commission 2005, Morgan et al 2005a,b).

#### **4.7.2 Homeless people**

It is estimated that between 30 and 50% of rough sleepers have mental health problems (SEU 1998). Two in three homeless people have physical health problems, and average life expectancy is 42 (St Mungo's, undated). One report suggests that half of homeless households where a person has a mental health problem also include someone with a physical health problem (Homelessness and Housing Support Directorate 2004).

However, one in three homeless people who need treatment for physical health problems are not receiving it (St Mungo's,

undated). As has been noted, registration with primary care is often problematic. Among those who do have access to primary care, many avoid going to a GP because of previous bad experiences, negative attitudes, and fears about how they will be treated and of possibly being refused a service (Pleace et al 1999, Riley et al 2003). Unless their physical condition is particularly painful or debilitating, many will have other more urgent priorities (Pleace et al 1999). Dedicated primary care services do exist in some cities, sometimes involving mobile clinics (Homeless Link Cymru 2006, Riley et al 2003). Some of these are limited by restricted hours and not being able to offer permanent registration, which undermines the quality and continuity of care that can be provided (Pleace et al 1999).

Problems with access to primary care mean that many homeless people turn to Accident & Emergency services instead, often presenting with advanced conditions (Homeless Link Cymru 2006, Riley et al 2003, SEU 1998). Although such services may be more accessible than primary care, their use may be both inappropriate and costly (Homeless Link Cymru 2006, Riley et al 2003).

#### **4.7.3 People in prisons**

Around 10% of people in prison have a psychosis and over half have some form of neurosis (Singleton et al 1998). Both groups are likely to have physical health problems as well (ibid). Around half of those who are sentenced to custody are not registered with a GP prior to being sent to prison (Prison Reform Trust 2005). The number of people in prison who have learning disabilities is not known: the limited current data are considered to be underestimates and more accurate identification is needed (Myers 2004).

Healthcare provision in prisons is now the responsibility of Primary Care Trusts in England and Local Health Boards in Wales, and prisoners are entitled to 'a similar level of health services as are available to members of the general public under the NHS' (HM Prison Service 2005). Although concerns have been expressed about the quality of provision provided, improvements in standards are gradually being implemented (Triggle 2006).

#### **4.7.4 People in in-patient psychiatric units**

Responsibility for the physical health of people in in-patient psychiatric units lies with their consultant psychiatrist. The Royal College of Psychiatrists is currently preparing a set of recommendations to ensure that psychiatrists monitor and address the physical health issues relating to mental healthcare. However, psychiatrists cannot be expected to be fully familiar with all primary care and physical healthcare issues.

Being in hospital can have an adverse effect on physical health. The side-effects of psychotropic medication, a lack of physical activity, lack of tobacco control policies, and poor food all contribute to a deterioration in physical health and poorer self-image (Dean et al 2001). Even the process of obtaining support for physical healthcare can be difficult, if staff are not able to provide appropriate advice or are reluctant to provide information (ibid).

Primary care input into in-patient psychiatric units is rare. One exception is a service for patients in an acute unit in inner London (Welthagen et al 2004). This resulted in a range of medical conditions being identified, referrals to other specialists, and provision of health promotion advice to virtually all the patients who were seen. However, demand outstripped capacity and the service had to be prioritised. The 5-year review of the NSF for Mental Health in England indicated that future work would include the development of 'a more flexible division of responsibilities between primary and secondary care' (DH 2004: 72).

#### **4.7.5 People in residential and nursing homes**

People living in residential or nursing homes may not always be able to register with a GP of their choice (Jacobs 2003). They may also experience problems in getting to see a GP, with requests being filtered by staff (ibid, ACO 2005). One study found that a third of homes paid retainer fees to GPs even though the services provided were not always additional to standard primary care (Jacobs 2003), and even though allocations to general practices are already weighted to take account of the needs of patients in residential care (Secretary of State for Health 2004). Other research found that such fees averaged around £40 per resident per year but could be as high as £150, and homes might need to pass these extra costs on to residents (ACO 2001, 2005; Jacobs 2003). Although the House of Commons Health Committee (2004)

recommended that retainer fees should be abolished, the Department of Health responded that extra GP services to assist in the management of business should be paid for (Secretary of State for Health 2004).

Despite the importance of food for both physical and mental health (Mental Health Foundation 2006), the quality of food provided to residents of residential and nursing homes can be less than ideal. A recent report found that 18% of residential homes for people with mental health problems and 14% of homes for people with learning disabilities in England did not meet the national minimum standards on meals (CSCI 2005). A fifth of older people living in institutions have been found to be malnourished (Stratton et al 2002). And three out of eight homes for adults under 65 in England fail to meet national minimum standards on medication: residents are given the wrong medication, someone else's medication, incorrect doses, or none of the prescribed medication (CSCI 2006). In Wales, too, the management of medication has been highlighted as a problem in 40% of care homes for adults (CSIW 2005).

Under the national minimum standards on care homes for adults, people under 65 in residential homes have to be offered annual health checks (DH 2003a). One survey found that 26% of general practices said they did this, though the overall response rate was only 23% (Dalby and Webster 2006). Responsibility for the cost of such checks is unclear, with the Department of Health maintaining that this should be included in the contracts between the providers and commissioners of care (unpublished correspondence).

#### **4.8 Health checks**

The value of regular health checks within the wider population has often been questioned. Checks for older people have tended to identify problems with social functioning rather than with health, while the costs of random checks for coronary heart disease and cancer among adults have been judged to outweigh their benefits (Hanlon et al 1995, Haq et al 1995, Iliffe et al 1999, Oxcheck Study Group 1995, Toon 1995).

##### **4.8.1 Health checks for people with learning disabilities**

The evidence in respect of health checks for people with learning disabilities, however, indicates that regular checks do identify previously unknown and unmet needs (Alborz et al 2006, Linehan

et al 2004). In Australia, Lennox et al (2001) reported that a comprehensive health assessment identified a range of overdue health maintenance activities, detected health problems, and could enable GPs to become aware of major health issues previously unknown to them. Beange et al (1995) found that checks revealed over five medical problems per person, half of which had not been detected previously; cardiovascular risk factors, in particular, were found to be significantly higher than in the local population. In New Zealand, checks resulted in 73% of people needing follow-up interventions (Webb and Rogers 1999).

A number of studies in the UK have reported similar results. A randomised controlled trial in Wales showed that regular screening highlighted new health problems (Kerr 1998). Unmet needs were similarly identified in a project in Scotland (Paxton and Taylor 1998). New health needs were found in 51% of people who had a check in Wales, including serious new health problems among 9% (Baxter et al 2006). In England, two studies found that 94% and 97% of people with learning disabilities were found to have a physical health problem that warranted intervention (Cassidy et al 2002, Alborz 2005). Two studies in Northern Ireland identified high rates of health problems, with 54% of the sample in the one study being referred to their GP for further assessment and treatment (Barr et al 1999, McConkey et al 2002). Crucially, Cooper et al (2006) found that health checks revealed more health needs than were identified in the course of routine care for people who did not have such checks, and they also resulted in more needs being met. Health checks have shown that routine health tests are often not being carried out: this applies, for instance, to blood pressure monitoring, tetanus immunisation, and height and weight measurement (Kerr et al 1996). A set of recommendations for routine screening has been produced by the International Association for the Scientific Study of Intellectual Disabilities (Lennox et al 2002).

Dalby and Webster (2006) found that 36% of general practices said they offered health checks to adults with learning disabilities; as noted earlier, the overall response rate was 23% and it is not known whether non-respondents would have been as likely to offer checks. Band (1998) reported that checks were more likely for young people up to the age of 19 than for older adults; they were also more frequent among people living in care settings than for those living with their families.

Follow-up checks, too, have identified health needs and further interventions that are required (Martin et al 2004). Kerr et al (2005), in an analysis for this investigation, found that subsequent checks after a year or more identified new health needs among 68% of their sample, with serious problems in 11%. Alborz (2005) suggests that it may not be possible to check every aspect of a person's health on a single occasion, especially if the person is anxious and a degree of familiarisation with health check procedures is needed. Sufficient time, too, is needed. Clinical considerations indicate that checks should be carried out annually (Alborz 2005).

Not all the checks reported here have been carried out by GPs. Some have been undertaken by community learning disability nurses (Barr et al 1999, McConkey et al 2002). Others have involved: practice nurses or health visitors working together with learning disability nurses (Alborz 2005, Paxton and Taylor 1998); practice nurses and GPs (Baxter et al 2006, Kerr et al 1996); or a consultant psychiatrist in learning disability working with a GP and community learning disability nurse (Cassidy et al 2002). The concept of a check being performed by the primary care team, involving a practice nurse and GP, is in keeping with usual healthcare practice in the UK. The involvement of community learning disability nurses or psychiatrists fits in less easily with such practice.

With effect from 2006, annual health checks for people with learning disabilities have been introduced as a directed enhanced service in Wales (Welsh Assembly Government 2006a). Practices have to compile their own registers of people with learning disabilities known to social services, invite them for checks, and carry out the check using a standard format. Extra funding at the rate of £100 per check has been provided by the Welsh Assembly Government. In England, the Government has sought to ensure that people with learning disabilities are aware that, under the new GP contract, they can ask for a health check if they have not seen a GP for three years (Department of Health 2004). Although mandatory health checks have been advocated (NHS Executive 1998) and considered (Department of Health 2003b), they have not yet been introduced. The emphasis has been, rather, on the need for service commissioners to recognise the health needs of people with learning disabilities (NHS Executive 1998), providing

guidance for primary healthcare teams (NHS Executive 1999), and information for people with learning disabilities themselves (e.g. Department of Health 1998). 'Valuing People' stressed the need to address avoidable illness and premature death among people with learning disabilities (DH 2001). Subsequent guidance focused on the provision of health action plans, in which people with learning disabilities and healthcare professionals should identify the actions needed to maintain and improve an individual's health (Department of Health 2002). The 2006 revision to the GP contract includes an indicator relating to the production of practice-based registers of people with learning disabilities (BMA and NHS Employers 2006). This would be a first step towards the provision of regular health checks.

#### **4.8.2 Physical health checks for people with mental health problems**

Given the increased risk of physical conditions such as CHD and diabetes (Osborn et al 2006) and the potential adverse effects of psychotropic medication (Lader 1999), the need for regular screening and interventions for people with mental health problems is also indicated. Annual health checks have been advocated (e.g. Seymour 2003), and Cohen and Phelan (2001) suggest that the frequent contacts to GPs by people with serious mental health problems provide an ideal opportunity to assess physical health needs in a structured way at least once a year. Although Burns and Cohen (1998) found that a structured assessment encompassing psychological, physical and social well-being, completed by practice nurses, did not lead to an improvement in healthcare, a study in the US showed that structured physical assessments of people with schizophrenia did help to identify physical illness (Jeste et al 1996).

The need for physical health checks is included in the NICE guidance on schizophrenia (NICE 2002). This specifically mentions the need to take account of cardiovascular risk factors (as indicated by blood pressure), blood sugar levels, the side-effects of medication, and lifestyle factors such as smoking. Physical health checks should also be included in assessments under the Care Programme Approach (CPA) and care plans should identify physical health needs (Department of Health, 1990). The extent to which the CPA is used to assess physical health needs is very variable. Some mental health trusts, for instance, only offer a check to people on enhanced CPA (for

people with more complex mental health problems). Resource constraints prevent other trusts from providing physical health screening alongside mental health assessment.

Both the English and Welsh National Service Frameworks (NSFs) for Mental Health (Department of Health 1999b, Welsh Assembly Government 2002) make specific recommendations about physical health, including the need for primary care services to ensure that people with mental health problems receive effective services to meet their physical health needs. Among the available training materials, a pack for GP educators from the Sainsbury Centre for Mental Health (Cohen and Hove 2001) discusses ways of implementing those recommendations. The importance of addressing premature death, higher morbidity, and lower rates of health promotion activity were also identified in the Social Exclusion Unit's report on mental health (SEU 2004). A five-year review of the English NSF noted that future work will include attention to physical health issues, including a reduction in smoking (DH 2004a). And the English White Paper on public health, 'Choosing Health', refers to the need to improve the physical health of people with mental health problems (DH 2004b).

Annual health checks for people with mental health problems are enshrined in the new GP contract, which includes financial incentives to provide such checks (DH 2004c). The revised (2006) version specifies that these should normally include: issues relating to alcohol or drug use; smoking and blood pressure; cholesterol checks where clinically indicated; BMI; the risk of diabetes from antipsychotic drugs; cervical cytology where appropriate; and accuracy of medication (BMA and NHS Employers 2006). The National Institute for Mental Health in England, in collaboration with others, has produced a leaflet for people with mental health problems encouraging them to seek such checks (NIMHE 2004). The revised contract includes an indicator relating to the percentage of people who do not attend their annual review and who are followed up by the practice (BMA and NHS Employers 2006). A separate indicator relates to reviews for people with dementia, including of physical health. In Wales, an additional directed enhanced service requires the production of an annual health report for people on enhanced CPA, which will be made available to the person's psychiatrist and CPA co-ordinator, and for which an additional fee will be paid (Welsh Assembly Government 2006b).

Regular checks were initially only required for people who agreed to their names being on a register (DH 2004c). This was amended in 2006: registers should now include all people with a diagnosis of schizophrenia, bipolar disorder and other psychoses, and the need for the individual to agree to regular follow-up has been removed (BMA and NHS Employers 2006). Although this overcomes incomplete coverage of checks resulting from some people's mistrust of registers, it means that names may now be included without people being aware of this. There is already evidence that some people with mental health problems are being invited to physical health checks without being told this is because they have a mental health problem (Wright et al 2006). Although people with serious mental health problems are often willing to attend physical health checks (Osborn et al 2003, Smith et al, forthcoming), some believe that registers are stigmatising (Wright et al 2006). Some staff, for their part, feel uncomfortable explaining that the invitation to a check is because of the mental health problem (Wright et al 2006).

A recent study in England and Wales found that only 31% of over 950 people with serious mental health problems had received a recent physical health check (Smith et al forthcoming). People were recruited to this study between 2003 and 2006, i.e. both before and after the new GP contract was introduced in 2004. Assessments of the whole sample, however, revealed high rates of obesity (49%), glucose abnormalities (12%), hypertension or pre-hypertension (50%) and hyperlipidaemia (71%), together with poor diet, low exercise levels and smoking: these indicate a need for a systematic approach to the identification and modification of risk factors for heart disease in particular.

A survey in early 2005, before the end of the first full year of the new GP contract, found that 72% of people with serious mental health problems said they had received a general health check in the past year (Rethink 2005b). However, only 51% of respondents mentioned having their blood pressure checked, 22% referred to blood glucose tests, and 31% said they had had their weight checked. Only 29% said they had been given lifestyle management advice. Some primary care staff have noted their lack of experience with mental health issues and the side-effects of antipsychotic medication: close liaison is then needed between the prescribers of such medication, usually psychiatrists, the

community mental health teams that support people with their mental health problems, and primary care teams which can provide interventions for physical health problems (Wright et al 2006). A review of the effectiveness of interventions to improve the physical health of people with mental health problems noted, similarly, that a joint approach involving both primary and secondary mental health services offers the best opportunity to address problems (Samele et al 2006b).

#### **4.9 Conclusion**

The range of health inequalities experienced by people with learning disabilities or mental health problems is extensive and a variety of specific actions is needed to address them. This paper has highlighted some of the key issues and the available evidence. The wider investigation, of which this paper forms a part, explores the solutions in more depth and sets out recommendations for Governments, commissioners of services, specialist mental health and learning disability providers, performance management, inspection and scrutiny bodies, and standard-setting and good practice organisations, as well as providers of primary care. The reduction of health inequalities requires concerted and focused efforts by all those organisations and individuals. Relying on existing policies and practices is not enough: even health inequalities strategies could unintentionally increase inequalities for people with learning disabilities or mental health problems if they fail to take account of their specific needs (Cooper et al 2004). In addition, more systematic recording and monitoring of healthcare provision and outcomes will be needed to demonstrate whether, and to what extent, the current gaps in health outcomes are reduced.

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