‘Key Highlights’ of Research Evidence on the Health of People with Learning Disabilities

**Mortality**

People with learning disabilities have an increased risk of early death compared to the general population (Hollins et al., 1998; McGuigan et al., 1995), although the life expectancy of this population is increasing over time and, for people with mild learning disabilities, approaching that of the general population (Carter & Jancar, 1983; Puri et al., 1995).

People with Down’s syndrome have a shorter life expectancy than people with learning disabilities generally, although the life expectancy of this group is increasing particularly quickly (Puri et al., 1995).

**Cancer**

Although the incidence of deaths from cancer in the UK is currently lower than the general population (11.7%-17.5% vs 26%), the incidence of cancer amongst people with learning disabilities is rapidly increasing due to increased longevity amongst this population (Cooke, 1997; Duff et al., 2001; Jancar, 1990).

People with learning disabilities have proportionally higher rates of gastrointestinal cancer than the general population (48%-58.5% vs 25% of cancer deaths) (Cooke, 1997; Duff et al., 2001; Jancar, 1990).

Children with Down’s syndrome are at particularly high risk of leukaemia compared to the general population, although the risk of solid tumours, including breast cancer, is lower (Hasle et al., 2000; Hermon et al., 2001; Satge et al., 1998).

Women with learning disabilities are much less likely to undergo cervical smear tests than the general population (19% vs 77%; Djuretic et al., 1999; 24% vs 82%; Pearson et al., 1998). Most women with learning disabilities undergoing cervical smear tests do not understand the purpose of the test (Broughton & Thomson, 2000).

Women with learning disabilities are much less likely to engage in breast cancer examinations or receive invitations to mammography than the general population (33%; Davies & Duff, 2001; 10%; Piachaud & Rohde, 1998; 43% vs 57%; Djuretic et al., 1999), despite a 90% attendance rate at mammography clinics (Davies & Duff, 2001).

**Coronary Heart Disease**

Studies of the incidence of coronary heart disease in the UK are lacking, although CHD is the second most common cause of death amongst people with learning disabilities (14%-20%; Hollins et al., 1998) and rates of CHD are increasing due to increased longevity and lifestyle changes associated with community living (Carter & Jancar, 1983; Turner & Moss, 1996; Wells et al., 1997).
Almost half of all people with Down’s syndrome are affected by congenital heart problems, a much higher rate than the general population (Brookes & Alberman, 1996; Hermon et al., 2001). Surgical treatment in Poland and the USA of congenital heart defects in children with Down’s syndrome produces a similar degree of positive benefit compared to children from the general population (Malec et al., 1999; Reller & Morris, 1998), although there is some evidence that cardiac surgery may be less likely to be offered to children with Down’s syndrome (Kmietowicz, 2001).

Respiratory Disease

Respiratory disease is the leading cause of death for people with learning disabilities (46%-52%; Carter & Jancar, 1983; Hollins et al., 1998; Puri et al., 1995), and is much higher than for the general population (15%-17%).

Primary Health Care

Although people with learning disabilities visit their GP with similar frequency to the general population, they are less likely to receive regular health checks (Kerr et al., 1996b; Welsh Office, 1995; Whitfield et al., 1996), including people with Down’s syndrome (Piachaud et al., 1998).

Most GPs agree that they should meet the medical needs of people with learning disabilities as part of general medical services, although fewer agree that they should take an active role, such as providing regular health checks (Bond et al., 1997; Ineichen & Russell, 1987; Kerr et al., 1996a; Stein, 2000).

People with learning disabilities discharged from long-stay hospitals require 4 times as much workload from GPs as people without learning disabilities, including more practice appointments, home visits, telephone contacts and consultations with practice nurses. Prescribing costs are 6 times greater (Chambers et al., 1998).

GPs are not routinely acting as the co-ordinator of health care for people with learning disabilities, and collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally poor (Thornton, 1999).

Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs (Barr et al., 1999; Howells, 1986; McGrother et al., 1996; Wilson & Haire, 1990).

Regular health screening of people with learning disabilities through co-operation between specialist learning disability teams, GPs and primary health care teams improves health status and access to other mainstream health services (Cassidy et al., 2002; Martin et al., 1997). Information to prompt GPs to take a more active role appears ineffective (Jones & Kerr, 1997).

Adults aged over 60 are less likely to receive a range of health services compared to younger adults with learning disabilities (Cooper, 1997c).
Secondary Health Care

There are significant variations in NHS total expenditure and expenditure per person on services for people with learning disabilities across different areas of England, with lower spending in rural areas (Forsyth & Winterbottom, 2002), and significant variation in the services provided to people with learning disabilities by specialist NHS Trusts (Bailey & Cooper, 1997).

People with learning disabilities have an increased uptake of medical and dental hospital services but a reduced uptake of surgical specialities compared to the general population, with a similar overall rate of hospital admissions and a reduced length of stay (Morgan et al., 2000). People with learning disabilities recently discharged from long-stay hospitals have a reduced uptake of non-psychiatric hospital admissions but a higher intake of psychiatric hospital admissions compared to people with learning disabilities not previously institutionalised (Morgan et al., 2000).

Re-admission rates to long-stay hospital for people with learning disabilities formerly resident in institutions is less than 10%, with a recent improvement in re-admission rates (Seager et al., 2000). Severe behavioural disturbance involving aggression to staff is the most common reason for re-admission, with mental health problems, uncontrolled epilepsy and other unmet physical health needs also given as reasons for re-admission (Seager et al., 2000).

Epilepsy

The prevalence rate of epilepsy amongst people with learning disabilities has been reported as 22% (Welsh Office, 1996), compared to prevalence rates for the general population of 0.4%-1% (Chadwick, 1994). Seizures are commonly multiple and refractory to drug treatment (Branford et al., 1998). Uncontrolled epilepsy can have serious negative consequences on both quality of life and the life span, although guidelines on the successful management of epilepsy in people with learning disabilities are available (Kerr & Bowley, 2001a, b; Working Group of the International Association of the Scientific Study of Intellectual Disability, 2001).

Sensory Impairments

People with learning disabilities are between 8.5 and 200 times more likely to have a vision impairment compared to the general population and around 40% are reported to have a hearing impairment, with people with Down’s syndrome at particularly high risk of developing vision and hearing loss (Carvill, 2001).

People with learning disabilities are unlikely to be assessed for vision or hearing impairments due to staff attributing lower levels of functioning to the persons’s learning disability (Lavis et al., 1997; Yeates, 1995), and are unlikely to receive aids to vision or hearing (McCulloch et al., 1996; Yeates, 1995).

Dementia

The prevalence of dementia is much higher amongst older adults with learning disabilities compared to the general population (21.6% vs 5.7% aged 65+; Cooper,
1997a), and is associated with a range of maladaptive behaviours (Cooper, 1997b) and health problems (Holland, 2000). People with Down’s syndrome are at particularly high risk of developing dementia, with an age of onset 30-40 years younger than the general population (Holland et al., 1998).

**Osteoporosis**

People with intellectual disabilities have substantially lower bone density than the general population (Aspray et al., 1998), with increased fractures occurring throughout the life span, particularly in people with learning disabilities and epilepsy (Jancar & Jancar, 1998).

**Oral Health**

36.5% of adults with learning disabilities and 80% of adults with Down’s syndrome have unhealthy teeth and gums (Barr et al., 1999), with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth (Tiller et al., 2001).

People with learning disabilities are most likely to receive dental care from community dental services, although coverage is considerably less than optimal (Pratelli & Gelbier, 1998; Tiller et al., 2001).

**Risk Factors Associated With Poor Health**

People with learning disabilities are much more likely to be either underweight or obese than the general population (Bell & Bhate, 1992; Messent et al., 1998; Robertson et al., 2000; Wood, 1994), with women, people with Down’s syndrome, people of higher ability and people living in less restrictive environments at increased risk of obesity (Bell & Bhate, 1992; Prasher, 1995; Robertson et al., 2000).

Less than 10% of adults with learning disabilities eat a balanced diet, with an insufficient intake of fruit and vegetables and a lack of knowledge and choice about healthy eating (Robertson et al., 2000; Rodgers, 1998).

Over 80% of adults with learning disabilities engage in levels of physical activity below the minimum recommended by the Department of Health, a much lower level of physical activity than the general population (53%-64%) (Messent et al., 1998; Robertson et al., 2000a), with people of lower ability in more restrictive environments at increased risk of inactivity (Robertson et al., 2000a).

Fewer adults with learning disabilities smoke tobacco or drink alcohol compared to the general population (Fidler et al., 1992; Robertson et al., 2000a), with no UK research on illegal drug use within this population.

**Mental Health**

Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% vs 1%; Doody
et al., 1998), with higher prevalence rates for South Asian adults with learning disabilities compared to White adults with learning disabilities (Chaplin et al., 1996).

Reported prevalence rates for anxiety and depression amongst people with learning disabilities vary widely, but are generally reported to be at least as prevalent as the general population (Stavrakaki, 1999), and higher amongst people with Down’s syndrome (Collacott et al., 1998).

Children with learning disabilities are more likely to experience anxiety disorders (8.7% vs 3.6%) and conduct disorders (25.0% vs 4.2%) than children without learning disabilities, although rates for depression are similar (1.5% vs 0.9%) (Emerson, 2003 in press).

Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49 (Emerson et al., 2001).

People with mental health problems and borderline intellectual functioning are particularly difficult to treat (Hassiotis et al., 1999) and people with learning disabilities are at risk of receiving no mental health service, due to the lack of communication between mainstream psychiatry services and learning disability psychiatry services (Hassiotis et al., 2000; Moss et al., 1996; Roy et al., 1997).

A very high proportion of people with learning disabilities are receiving prescribed psychotropic medication, most commonly anti-psychotic medication (40%-44% long-stay hospitals; 19%-32% community-based residential homes; 9%-10% family homes; Branford, 1994; Clarke et al., 1990; Robertson et al., 2000b). Anti-psychotics are most commonly prescribed for challenging behaviours rather than schizophrenia, despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side-effects (Emerson, 2001).

HIV

No data are available concerning the prevalence or HIV amongst people with learning disabilities, although some adults with learning disabilities are known to engage in behaviours placing them at risk of contracting HIV and effective HIV education and prevention services for people with learning disabilities are scarce (Cambridge, 1995, 1996, 1997; Dent et al., 1994; MacDonald et al., 1999; Thompson, 1994).

Thyroid Dysfunction

Children and adults with Down’s syndrome are at increased risk of thyroid dysfunction, particularly hypothyroidism, compared to the general population, with the incidence of thyroid dysfunction increasing with age (Loudon et al., 1985; Rooney & Walsh, 1997)
References


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With thanks to:
Colin Espie, James Hogg, Theresa Joyce, Janet Robertson and Irene Tuffrey-Wijne