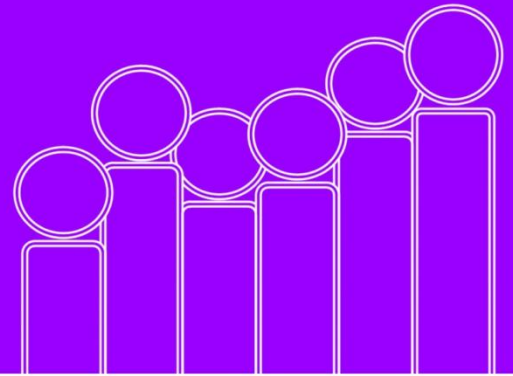




Improving Health and Lives:
Learning Disabilities Observatory

Health Inequalities & People with Learning Disabilities in the UK: 2010

Eric Emerson and Susannah Baines



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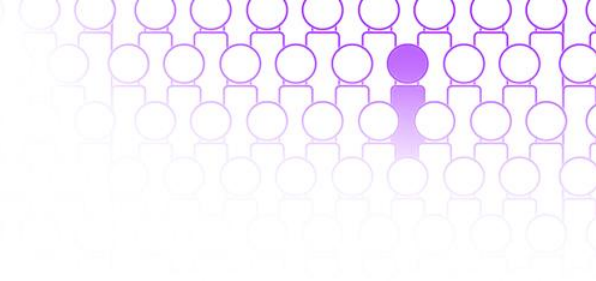
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About the Authors

Eric Emerson is Co-Director of the Improving Health and Lives Learning Disabilities Observatory. Eric is also Professor of Disability & Health Research at the [Centre for Disability Research](#), School of Health & Medicine, Lancaster University and Visiting Professor at the [Australian Family and Disabilities Studies Research Collaboration](#), University of Sydney.

Susannah Baines is a Research Associate with the Improving Health and Lives Learning Disabilities Observatory, and is based at the [Centre for Disability Research](#), School of Health & Medicine, Lancaster University.



Introduction

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable.¹⁻¹⁴

The health inequalities faced by people with learning disabilities in the UK start early in life,¹⁵⁻²⁰ and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care.²¹⁻²⁷ The inequalities evident in access to health care are likely to place many NHS Trusts in England in contravention of their legal responsibilities defined in the Disability Discrimination Acts 1995 and 2005 and the Mental Capacity Act 2005. At a more general level, they are also likely to be in contravention of international obligations under the UN Convention on the Rights of Persons with Disabilities.²³

The Department of Health have continuously emphasised that Primary, Acute and Specialist NHS Trusts must play in a central role in meeting the health needs of people with learning disabilities.^{24 25 27 28}

This briefing paper will assist Primary, Acute and Specialist NHS Trusts in fulfilling their responsibilities. In this report we summarise the most recent evidence from the UK on the health status of people with learning disabilities and the determinants of the health inequalities they face. Later in the autumn, IHaL will be producing a briefing for GP Commissioning Consortia and PCTs on practical commissioning actions to help address the issues identified in this report.

Inequalities in Health Status

In 2002 we undertook a comprehensive review of the UK research literature on the health needs of people with learning disabilities and the response of health services to people with learning disabilities.⁹ We have updated this review to include information published since 2002. As in the previous review, we have focused on information relating to the health needs of people with learning disabilities in the UK. We have, however, drawn attention to studies from other countries where these are particularly relevant.

In this section we summarise the available UK research literature concerning the health status and needs of children and adults with learning disabilities. Evidence concerning health needs in priority areas for the NHS is reviewed, along with additional areas of particular significance for people with learning disabilities.

Mortality

People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population.^{29 30} Life expectancy is increasing, in particular for people with Down's syndrome, with some evidence to suggest that for people with mild learning disabilities it may be approaching that of the general population.³¹ All cause mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population, with mortality being particularly high for young adults, women and people with Down's syndrome.³²

General Health Status

The risk of children being reported by their main carer (usually their mother) to have fair/poor general health is 2.5-4.5 times greater for children with learning disabilities when compared to their non-disabled peers.^{17 18} One in seven adults with learning disabilities rate their general health as not good.³³ These maybe underestimates of the poorer health of people with learning disabilities as carers of people with learning disabilities tend to perceive the person they care for to be healthier than suggested by the results of medical examination.^{34 35} Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs.^{34 36-39}

Cancer

Overall, the incidence of deaths from cancer in the UK among people with learning disabilities is currently lower than the general population (12%-18% vs 26%), although people with learning disabilities have proportionally higher rates of gastrointestinal cancer than the general population (48%-59% vs 25% of cancer deaths).⁴⁰⁻⁴² However, the incidence and pattern of cancer amongst people with learning disabilities is rapidly changing due, in part, to increased longevity.⁴⁰⁻⁴² 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.^{43 44} There is a high prevalence of helicobacter pylori, a class 1 carcinogen linked to stomach cancer, gastric ulcer and lymphoma, among people with learning disabilities.⁴⁵

Coronary Heart Disease

Coronary heart disease is a leading cause of death amongst people with learning disabilities (14%-20%),²⁹ with rates expected to increase due to increased longevity and lifestyle changes associated with community living.⁴⁶ Almost half of all people with Down's syndrome are affected by congenital heart defects.^{44 47}

Respiratory Disease

Respiratory disease is possibly the leading cause of death for people with learning disabilities (46%-52%), with rates much higher than for the general population (15%-17%).^{29 31} People with asthma and learning disabilities were found to be twice more likely to be smokers than patients with learning disabilities who do not have asthma. More than half of women with learning disabilities and asthma are also obese.⁴⁸

Mental Health & Challenging Behaviour

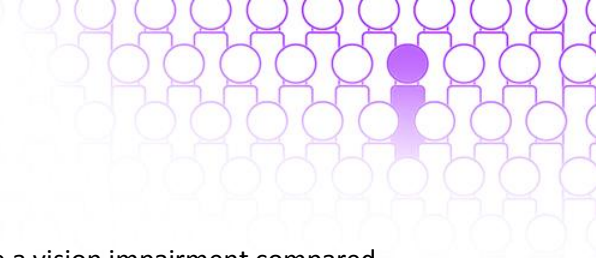
The prevalence of psychiatric disorders is 36% among children with learning disabilities, compared to 8% among children without learning disabilities, with children with learning disabilities accounting for 14% of all British children with a diagnosable psychiatric disorder.^{19 49} Increased prevalence of psychiatric disorder is particularly marked for autistic spectrum disorder (OR 33.4), ADHD/hyperkinesia (OR 8.4) and conduct disorders (OR 5.7).^{19 49} The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to general population rates.⁵⁰⁻⁵² 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 49.⁵³⁻⁵⁸ In some instances, challenging behaviours result from pain associated with untreated medical disorders.^{54 59 60} Reported prevalence rates for anxiety and depression amongst adults with learning disabilities vary widely, but are generally reported to be at least as prevalent as the general population and higher amongst people with Down's syndrome.⁶¹ There is some evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population, with higher prevalence rates for South Asian adults with learning disabilities compared to White adults with learning disabilities.^{62 63}

Dementia

The prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population (22% vs 6% aged 65+), and is associated with a range of potentially challenging behaviours and health problems.^{64 65} People with Down's syndrome are at particularly high risk of developing dementia, with the age of onset being 30-40 years younger than that for the general population.⁶⁶ Amongst people with moderate to profound learning disabilities, deaths from dementia are more common in men than women.⁶⁷

Epilepsy

The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least twenty times higher than for the general population, with seizures commonly multiple and resistant to drug treatment.⁶⁸⁻⁷⁰ Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality.^{71 72}



Sensory Impairments

People with learning disabilities are 8-200 times more likely to have a vision impairment compared to the general population.⁷³ Approximately 40% of people with learning disabilities are reported to have a hearing impairment, with people with Down's syndrome at particularly high risk of developing vision and hearing loss.⁷³ Those living independently or with family are significantly less likely to have had a recent eye examination than those living with paid support staff.⁷⁴ Carers frequently fail to identify sensory impairments, including cerebral visual impairment, among people with learning disabilities that they are supporting.^{38 75 76}

Physical Impairments

Among adults with learning disabilities, being non-mobile has been associated with a sevenfold increase in death and being partially mobile has been associated with a twofold increase of death when compared with being fully mobile.³² A population-based study in the Netherlands reported that people with learning disabilities are 14 times more likely to have musculo-skeletal impairments.⁷⁷

Oral Health

One in three adults with learning disabilities and four out of five adults with Down's syndrome have unhealthy teeth and gums,³⁶ with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth.⁷⁸

Dysphagia

Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. Among adults with learning disabilities, 40% of people with dysphagia experience recurrent respiratory tract infections. Other negative health consequences of dysphagia include asphyxia, dehydration and poor nutritional status.⁷⁹

Diabetes

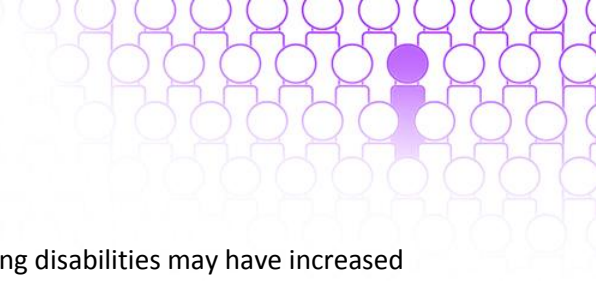
Increased rates of diabetes among adults with learning disabilities have been reported in a population-based study undertaken in the Netherlands.⁸⁰ We are not aware of any UK-based data on the prevalence of diabetes among people with learning disabilities.

Gastro-oesophageal Reflux Disease (GORD)

GORD causes pain and may contribute to sleep disturbance, problem behaviour, anaemia and risk of oesophageal cancer.⁵ Close to half of a sample of institutionalised people with moderate and severe learning disabilities in the Netherlands were found to have GORD.⁸¹ We are not aware of any UK-based data on the prevalence of GORD among people with learning disabilities.

Constipation

Constipation has been reported among two-thirds of a sample of institutionalised people with moderate and severe learning disabilities in the Netherlands.⁸² We are not aware of any published UK-based data on the prevalence of constipation among people with learning disabilities. However, an unpublished study has reported rates of constipation in the previous year ranging from 17% to 51% among adults with learning disabilities in varying types of supported accommodation.⁸³



Osteoporosis

Studies from Australia and the USA indicate that people with learning disabilities may have increased prevalence of osteoporosis and lower bone density than the general population.⁸⁴⁻⁸⁶ Contributory factors include lack of weight-bearing exercise, delayed puberty, earlier-than-average age at menopause for women, poor nutrition and being underweight. Fractures can occur with only minor injury and can be multiple.⁵ We are not aware of any UK-based data on the prevalence of osteoporosis among people with learning disabilities.

Endocrine Disorders

Hypothyroidism is relatively common among people with Down's syndrome, prevalence increasing with age. Prevalence rates in children with Down's syndrome have been reported to range from 9%-19%.⁸⁷⁻⁸⁹ A prevalence rate of 22% has been reported in an institutionalised population of adults with Down's syndrome.⁹⁰

Injuries, Accidents and Falls

High rates of accidents and injuries amongst people with learning disabilities, including injuries from falls, have been reported in studies undertaken in Canada, Australasia, the Netherlands and the US.⁹¹⁻⁹⁵ In Denmark and Australia, accidents have been reported to be a more common cause of death among people with learning disabilities than in the general population.⁵ We are not aware of any UK-based data on the prevalence of injuries, accidents or falls among people with learning disabilities.



Determinants of Health Inequalities

Research studies have investigated five broad classes of determinants of the health inequalities faced by people with learning disabilities that are, in principle, potentially amenable to intervention.

- Increased risk of exposure to well established ‘social determinants’ of health;
- Increased risk associated with specific genetic and biological causes of learning disabilities;
- Communication difficulties and reduced health ‘literacy’;
- Personal health risks and behaviours;
- Deficiencies in access to and the quality of healthcare provision.

Evidence for these determinants of health inequalities (which are not presented in any priority order) is outlined below.

The ‘Social Determinants’ of Health

People with learning disabilities, especially people with less severe learning disabilities, are more likely to be exposed to common ‘social determinants’ of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.^{4 96-100} The association between exposure to such adversities and health status is at least as strong among people with learning disabilities as it is among the general population.^{19 101} It has been estimated that increased exposure to low socio-economic position/poverty may account for: (1) 20–50% of the increased risk for poorer health and mental health among British children and adolescents with learning disabilities;¹⁷⁻¹⁹ (2) 29-43% of the increased risk for conduct difficulties and 36-43% of the increased risk for peer problems among Australian children with learning disabilities or borderline intellectual functioning;¹⁰² (3) a significant proportion of increased rates of self reported antisocial behavior among adolescents with learning disabilities;¹⁰³ and (4) 32% of the increased risk for conduct difficulties and 27% of the increased risk for peer problems among a nationally representative sample of 3 year old British children with developmental delay.¹⁰⁴ Exposure to bullying at school and overt discrimination in adulthood are independently related to poorer health status of people with learning disabilities.⁹⁷ Given the association between minority ethnic status and poverty and the exposure of people with learning disabilities from minority ethnic communities to overt racism,¹⁰⁵ it is likely that people with learning disabilities from minority ethnic communities will face greater health inequalities than people with learning disabilities from majority ethnic communities.

Genetic & Biological Factors

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities.⁶⁷ In addition a number of syndromes associated with learning disabilities are also associated with some specific health risks.^{54 106-108} For example:

- congenital heart disease is more prevalent among people with Down's syndrome and Williams syndrome;
- early onset dementia is more common in people with Down's syndrome;
- hypothalamic disorders are more prevalent among people with Prader-Willi syndrome;
- mental health problems and challenging behaviours are more prevalent among people with autism spectrum disorders, Rett syndrome, Cornelia de Lange syndrome, Riley-Day syndrome, Fragile-X syndrome, Prader-Willi syndrome, Velocardiofacial syndrome, Williams syndrome and Lesch-Nyhan syndrome;
- obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome and Bardet-Biedl syndrome.

Communication & Health Literacy

People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses.¹⁰⁹⁻¹¹¹ In addition, limited communication skills may reduce their capacity to convey identified health needs effectively to others (e.g., relatives, friends, paid support workers). As a result, carers (unpaid and paid) play an important role in the identification of health needs for many people with more severe learning disabilities. However, they may have difficulty in recognizing expressions of need, particularly if the person concerned does not communicate orally.^{38 112} People with learning disabilities experience a lack of knowledge and choice about healthy eating.¹¹³

Personal Health Risks & Behaviours

Diet

Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables.¹¹⁴ Carers generally have a poor knowledge about public health recommendations on dietary intake.¹¹⁵

Exercise

Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53%-64%).^{114 116 117} People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity.¹¹⁴

Obesity & Underweight

People with learning disabilities are much more likely to be either underweight or obese than the general population.^{16 114 116-119} Women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity.^{114 117 119 120} The high level of overweight status amongst persons with learning disabilities is likely to be associated with an increased risk of diabetes.⁵

Substance Use

Fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population.^{114 121} However, rates of smoking among adolescents with mild learning disability are higher than among their peers.¹²² Within a sample of people with learning disabilities who admitted to substance misuse, 61% were male, and alcohol was the most misused substance.¹²³

Sexual Health

Little is known about inequalities in the sexual health status of people with learning disabilities in the UK. There is, however, evidence to suggest that they may face particular barriers in accessing sexual health services, and the informal channels through which young people learn about sex and sexuality.¹²⁴ A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases.⁷⁷ High rates of unsafe sexual practices has been reported among gay men with learning disabilities.¹²⁵

Access to and the Quality of Healthcare

A range of organisational barriers to accessing healthcare services have been identified.^{22 23 27 60 126 127}

These include:

- scarcity of services;
- physical barriers to access;
- failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- variability in the availability of interpreters for people from minority ethnic communities;
- 'diagnostic overshadowing' (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities);
- disablist attitudes among healthcare staff.

Consent

The National Patient Safety Agency has reported concern about 'consent being sought from a carer rather than taking the time to gain consent from the person with the learning disability.'¹²⁸

Health Screening and Health Promotion

A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities.^{126 127} These include:

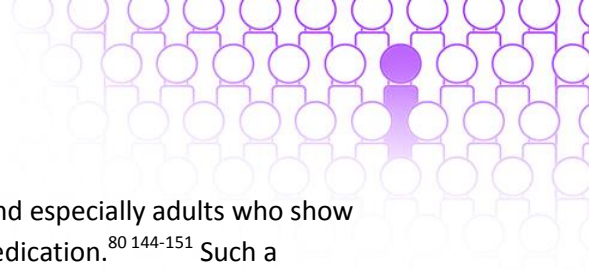
- Assessment for vision or hearing impairments;^{129 130}
- Routine dental care;^{36 99}
- Cervical smear tests;¹³¹⁻¹³³
- Breast self-examinations and mammography.^{132 134-136}

Access to health promotion may be significantly poorer for people with more severe learning disabilities.¹⁵

Primary Health Care

Whilst people with learning disabilities visit their GP with similar frequency to the general population, they are less likely to receive regular health checks.¹³⁷⁻¹³⁹ Given the evidence of greater health need it would be expected that people with learning disabilities should be accessing primary care services more frequently than the general population. For example, comparison of general practitioner consultation rates to those of patients with other chronic conditions suggests that primary care access rates for people with learning disabilities are lower than might be expected.¹⁴⁰

Collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally regarded as poor.¹⁴¹ Adults aged over 60 with learning disabilities are less likely to receive a range of health services compared to younger adults with learning disabilities.¹⁴² The introduction of special health checks for people with learning disabilities has been shown to be effective in identifying unmet health needs, suggesting that health checks represent a 'reasonable adjustment' to the difficulties in identifying and/or communicating health need experienced by people with learning disabilities.³⁹ While providing financial incentives to GPs may influence practice, incentives based on general population health need may be insufficient to improve the quality of care for people with learning disabilities.¹⁴³



In the UK, and in other countries, adults with learning disabilities, and especially adults who show challenging behaviours, are commonly prescribed anti-psychotic medication.^{80 144-151} Such a widespread 'off-label' use of anti-psychotic medication is of concerns as: (1) there is little evidence that anti-psychotics have any specific effect in reducing challenging behaviours; (2) such medication has a number of well documented serious side effects.⁵⁴

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 areas¹⁵² and significant variation in the services provided to people with learning disabilities by specialist NHS Trusts.¹⁵³ 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.¹⁵⁴ People with learning disabilities with cancer are less likely to: be informed of their diagnosis and prognosis; be given pain relief; and less likely to receive palliative care.^{155 156}

Concern has been expressed with regard to the availability of and access to mental health services by people with learning disabilities.¹⁵⁷⁻¹⁵⁹ However, 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).^{144 148-150 160 161} 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.⁵⁴

Conclusions

Responding to the health inequalities faced by people with learning disabilities is a critically important issue for primary and secondary healthcare services in England. It is clear that these health inequalities are, to an extent, avoidable. It is also clear that existing patterns of healthcare provision are insufficient, inequitable and likely to be in contravention of legal requirements under the Disability Discrimination Acts 1995 and 2005 and the UN Convention on the Rights of Persons with Disabilities.²¹⁻²⁶

Department of Health policies and guidance have continuously emphasised the central role that mainstream health services must play in meeting the health needs of people with learning disabilities.^{24 25 28}

The health inequalities faced by people with learning disabilities make a significant contribution to overall health inequalities. Progress on reducing health inequalities in general will require greater attention to the health inequalities faced by particular 'high risk' groups, including people with learning disabilities.^{4 162}

This briefing paper has drawn attention to:

- those aspects of health where people with learning disabilities fare particularly poorly;
- current knowledge concerning the determinants of the health inequalities faced by people with learning disabilities.

Understanding the determinants of health inequalities helps identify potential solutions.^{162 163}

Responding appropriately to the health inequalities faced by people with learning disabilities in England demands action on several fronts. These include:

- reducing the exposure of people with learning disabilities to common social determinants of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination;
- improving the early identification of illness among people with learning disabilities by, for example, increasing uptake of annual health checks, and for women, cervical and breast screening.¹⁶⁴ Knowledge of the health risks associated with specific syndromes is of value in targeting the content of health checks;
- enhancing the health literacy of people with learning disabilities and of family carers and paid carers/supporters who play a critical role in promoting healthy lifestyles among many people with learning disabilities;
- making 'reasonable adjustments' in all areas of health promotion and healthcare in light of the specific needs of people with learning disabilities and acting within the legal framework of the Mental Capacity Act 2005 (e.g., through providing more accessible information and longer appointment times);
- monitoring progress towards the elimination of health inequalities faced by people with learning disabilities.

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