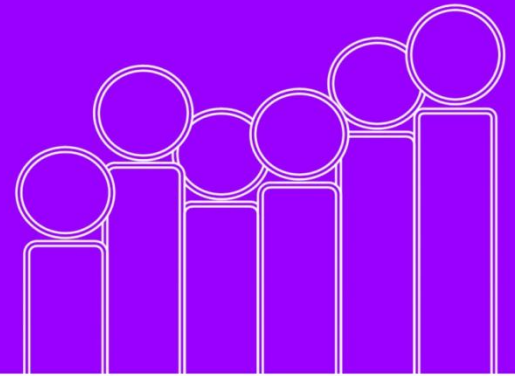




Improving Health and Lives:
Learning Disabilities Observatory

Health Inequalities & People with Learning Disabilities in the UK: 2011

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and Vicki Welch



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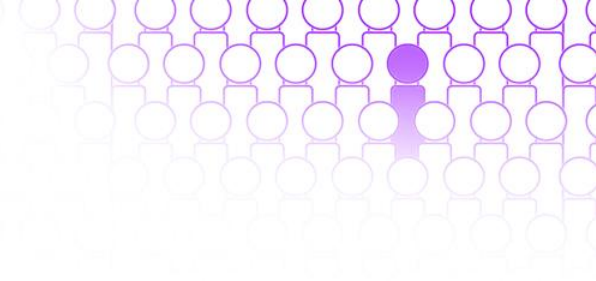
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Introduction

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable [1-17]. As such, these differences represent health *inequalities* [18].

The health inequalities faced by people with learning disabilities in the UK start early in life [19-24] and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care [25-31]. 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 Equality Act 2010, the Mental Capacity Act 2005 and the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. 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 [27].

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. 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]. This was updated in 2010 [32] to include information published since 2002 and has again been further updated for this edition in 2011. As in the previous reviews we have focused on information relating to the health needs of people with learning disabilities in the UK. We have, however, drawn attention to some studies from other countries where the results are particularly relevant. For this 2011 edition we have also included a further section focused on recent evidence of health inequalities and determinants relevant to children with learning disabilities, including new analyses of data extracted from the Millennium Cohort Study and the Longitudinal Study of Young People in England.

The Department of Health have repeatedly emphasised that Primary, Acute and Specialist NHS Trusts must play in a central role in meeting the health needs of people with learning disabilities [28, 29, 31, 33]. This briefing paper will assist those involved in commissioning health services and Primary, Acute and Specialist NHS Trusts in fulfilling their responsibilities. This report is accompanied by a separate report which provides detailed practical guidance for commissioners on strategies for reducing the health inequalities experienced by people with learning disabilities [34].



Inequalities in Health Status

We begin by summarising 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 [35-37]. 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 [38]. Nonetheless, 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 [39].

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 [21, 22]. One in seven adults with learning disabilities rate their general health as not good [40]. These may be 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 examinations [41, 42]. Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs [41, 43-47].

Cancer

Overall, the proportion of people with learning disabilities who die from cancer in the UK is lower than the general population (12%-18% vs 26%), although people with learning disabilities have proportionally higher rates of gastrointestinal cancer (48%-59% vs 25% of cancer deaths) [48-50]. However, the incidence and pattern of cancer amongst people with learning disabilities is rapidly changing due, in part, to increased longevity [48-50]. 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 [51, 52]. 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 [53]. In one study helicobacter pylori antibody tests indicated infection in 59% of residents of inpatient units for people with learning disability and 84% of those residents who had a history of being a long-stay resident (4 years or more) in hospital [54].

Coronary Heart Disease

Coronary heart disease is a leading cause of death amongst people with learning disabilities (14%-20%) [35], with rates expected to increase due to increased longevity and lifestyle changes associated with community living [55]. Almost half of all people with Down's syndrome are affected by congenital heart defects [52, 56].



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%) [35, 38]. People with asthma and learning disabilities were found to be two times 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 [57].

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 [23, 58]. These issues are discussed further in relation to children later in this report. Increased prevalence of psychiatric disorder is particularly marked for people with autistic spectrum disorder (OR 33.4), ADHD/hyperkinesia (OR 8.4) and conduct disorder (OR 5.7) [23, 58, 59].

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 [60-66]. In a recent study self injurious behaviour was recorded for 27% of individuals (children and adults) with learning disability, the same study reported such behaviour for between 45% and 93% for people with certain genetic syndromes [67]. In some instances, challenging behaviours result from pain associated with untreated medical disorders [61, 68-71].

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to general population rates [72-74]. Reported prevalence rates for anxiety and depression amongst adults with learning disabilities vary widely, but are generally at least as high as in comparison groups drawn from the general population. Anxiety and depression are particularly common amongst people with Down's syndrome [75]. There is some evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities may be three times greater than for the general population, with South Asian adults with learning disabilities having a higher prevalence than White adults with learning disabilities [76-78]. In one recent study people with learning disability who lived with their families were found to be more likely to have anxiety disorders whilst those who lived independently of their family were more likely to have personality disorders and overall higher rates of psychopathology [79]. Adults with learning disability who have ADHD have been shown to be more severely affected by mental health problems and less likely to improve over time than other people with ADHD [80].

It has been estimated that between 20% and 33% of people with learning disabilities known to local authorities also have an autistic spectrum disorder [81]. Similarly a recent study of children aged 10-14 who had a current diagnosis of an autistic spectrum disorder found that 55% also had a learning disability [82]. In a recent study examining mental health in people with learning disability and autistic spectrum disorder it was found that men and women had different mental health needs, for example schizophrenia and personality disorder were more common in men [83]. Similarly, other authors draw attention to the differing mental health needs of men and women with learning disability [84].

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 [85, 86]. Similarly one study reported a Standardised Morbidity Ratio of 3.9 (95% CI 2.5–5.7) for adults with learning disability aged 65 years and over when compared to prevalence reported for people from the general population [87]. 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 [88]. Amongst people with moderate to profound learning disabilities, deaths from dementia are more common in men than women [89], however dementia itself has been found to be more common in women [83].

Epilepsy

The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least 20 times higher than for the general population, with seizures commonly being multiple and resistant to drug treatment [90-93]. Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality [94, 95]. The relationship between epilepsy and mental health problems among people with learning disability is unclear; while one recent study has reported that people with epilepsy were less likely to have schizophrenia spectrum, anxiety and personality disorders [93], another has reported that the one year incidence rate for commonly occurring psychiatric disorders was up to seven times higher for people with epilepsy [96].

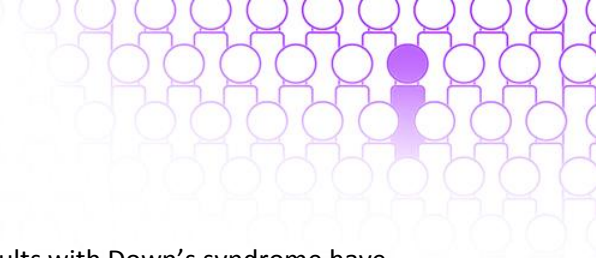
A recent review of English language papers found evidence of the misdiagnosis of epilepsy in people with learning disabilities; this includes both false positives and false negatives and may result in inappropriate treatment [97]. Antiepilepsy medication is associated with a number of problems such as broken sleep for some people with learning disability [98]. A recent U.S study suggests that some of the side effects of antiepilepsy medication may be greater for people with learning disabilities [99].

Sensory Impairments

People with learning disabilities are 8-200 times more likely to have a visual impairment compared to the general population [100]. Of people known to services in the UK it is estimated that 50,000 have a visual impairment and a further 15,000 are blind, many more adults with learning disabilities not known to services may have visual impairments or blindness [101]. 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 [100]. Those living independently or with family are significantly less likely to have had a recent eye examination than those living with paid support staff [102]. Carers of people with learning disabilities frequently fail to identify sensory impairments, including cerebral visual impairment [45, 103, 104].

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 [39]. A population-based study in the Netherlands reported that people with learning disabilities are 14 times more likely to have musculo-skeletal impairments [105].



Oral Health

One in three adults with learning disabilities and four out of five adults with Down's syndrome have unhealthy teeth and gums [43], with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth [106]. One study found that compared to older adults in the general population, older adult participants in the 2005 Special Olympics were less likely to have 21 or more teeth and gum inflammation was common, however they found that participants had fewer fillings and less evidence of untreated decay than the general population [107].

Dysphagia

Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. Chadwick and Jolliffe estimate that this problem affects a little more than 8% of adults known to learning disability services [108]. Forty percent of those with learning disabilities and dysphagia experience recurrent respiratory tract infections; other negative health consequences including asphyxia, dehydration and poor nutritional status [108, 109].

Diabetes

Increased rates of diabetes among adults with learning disabilities have been reported in population-based studies undertaken in the Netherlands and USA [110, 111]. We are not aware of any UK-based data on the prevalence of diabetes among people with learning disabilities.

Gastro-Oesophageal Reflux Disease (GORD)

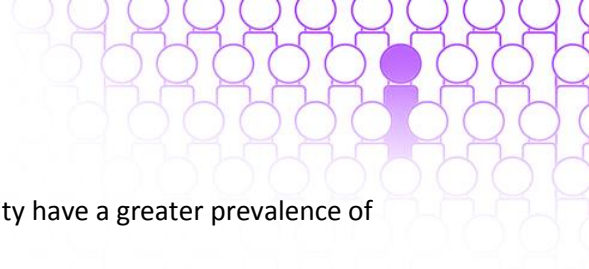
GORD causes pain and may contribute to sleep disturbance, problem behaviour, anaemia and risk of oesophageal cancer [5]. Close to half of a sample of institutionalised people with moderate and severe learning disabilities in the Netherlands were found to have GORD [112]. We are not aware of any UK-based 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 [113]. 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 [114]. People with learning disability may be more likely to be taking drugs associated with side effects which include constipation, however diagnosis of constipation is often missed due to communication problems [115].

Osteoporosis

Studies from other countries indicate that people with learning disabilities may have increased prevalence of osteoporosis and lower bone density than the general population [116-120]. Contributory factors include lack of weight-bearing exercise, delayed puberty, earlier-than-average age at menopause for women, poor nutrition, being underweight and use of anti-epilepsy medication. 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, but



one recent UK study has identified that people with learning disability have a greater prevalence of some risk factors for osteoporosis than other people [121].

Endocrine Disorders

Hypothyroidism is relatively common among people with Down's syndrome, with prevalence increasing with age. Reported prevalence rates in children with Down's syndrome range from 9%-19% [122-124]. A marginally higher prevalence rate (22%) has been reported in an institutionalised population of adults with Down's syndrome [125]. The difference between these rates is not statistically significant. One recent study found gradual improvements in thyroid hormone levels over a 15 year follow-up period and suggests that the incidence of definite hypothyroidism in people with Down's syndrome may be somewhat lower than would have been expected based on earlier prevalence studies [126]. There is evidence that children with profound learning disabilities are at greater risk of experiencing short stature due to untreated growth hormone deficiency [127].

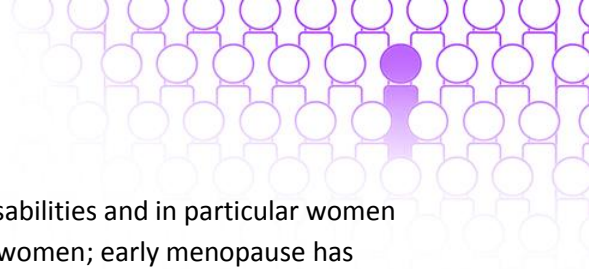
Injuries, Accidents and Falls

One recent UK study has found evidence that adults with learning disabilities experience higher rates of injuries and falls when compared to the general population [128]. High rates of accidents and injuries amongst people with learning disabilities, including injuries from falls, have also been reported in studies undertaken in Canada, Australasia, the Netherlands and the US [129-133]. 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].

Women's Health

Women with learning disabilities experience problems with menstruation such as heavy periods, premenstrual syndrome and painful periods as often as other women, however, these problems may not be appropriately recognised by carers and may be experienced differently or more negatively [134]. Parents and carers often feel that women with learning disabilities will not cope well with menstruation, in these circumstances they may seek medical help to suppress or eliminate periods using medication, hormonal intrauterine devices or various forms of surgery [135, 136]. Whilst effective, these treatments may also result in a series of negative side effects such as reduction in bone mineral density, weight gain, increased risk of thromboembolism, breast or cervical cancer, infection, sterility and necessity for invasive surgery [135]. Conversely a number of authors conclude that with support and appropriate education most women with learning disabilities can manage their own menstrual care [137, 138].

It has been noted that women with learning disabilities have markedly different patterns of contraceptive use to women in the general population with greater use of long term methods such as depot injection, oral contraceptive, intrauterine device or sterilisation and significantly less use of barrier methods [139, 140]. Evidence suggests that women with learning disabilities are not given sufficient information or fully involved in decisions about contraception [139, 141, 142]. Furthermore there is evidence that women are prescribed contraception even when they are not sexually active or are past child bearing age [139]. A study of nine UK women with learning disabilities who had been sterilized for contraceptive purposes found that none were reported to have been sexually active during a 20 year follow up period [143].



Studies in other countries have shown that women with learning disabilities and in particular women with Down's syndrome tend to have earlier menopause than other women; early menopause has also been found to be associated with dementia [144, 145]. A recent UK study found that women with learning disabilities had similar experiences of menopausal symptoms to other women but that they had poorer understanding of menopause and menstruation [146]. The same authors note elsewhere that carers report being poorly trained and resourced to help women understand the menopause [147]. An Australian study found that women with learning disabilities had greater risk of adverse pregnancy and birth outcomes including greater rates of pre-eclampsia and low birth weight [148].

Children and Health Inequality

Children with learning disabilities are subject to many of the health inequalities discussed above, however the evidence base is fragmented and studies tend to concentrate on the outcomes of specific conditions rather than giving insight into health inequality [17]. In this section we provide new analyses of data from the Millennium Cohort Study and the Longitudinal Study of Young People in England (see boxes on next two pages) and summarise findings from recent research.

Recent Research on Children and Health Inequality

Epilepsy

The prevalence of epilepsy in the British population is between 0.5% and 1%; among those with moderate learning disability this prevalence rises to 15% and among those with severe and profound disability the rate rises further to 30% [97]. In a study in one area of England, epilepsy prevalence in children between age 11 and 16 was 2.8 per 1000, whilst it was 28 per 1000 among children with special educational needs [149]. Moreover, seizures were considered well controlled in 78% of children without special educational needs in comparison with 41% of children with special educational needs. The relationship between epilepsy and learning disability may be bidirectional; the prevalence of cognitive impairment among children with epilepsy is approximately 20-30%, with some studies reporting increases in group IQ when surgery is performed to treat epilepsy [150].

Autism Spectrum Disorders

The current prevalence of ASD is estimated to be between 60 and 116 per 10,000 children [82]. Numerous studies have reported the prevalence of learning disability among children with ASD, with estimates ranging from 15% to 84% [81, 82]. The Special Needs and Autism Project (SNAP) examined 156 children with special educational needs or ASD diagnosis, of which 39.4% had mild learning disability, 8.4% had moderate learning disabilities and 7.4% had severe or profound learning disabilities. In contrast, 16.6% were above the threshold for learning disabilities but below average IQ and 25.4% were in the average IQ range.

The Health of Seven Year Old Children with Learning Disabilities in the UK

The Millennium Cohort Study is tracking the well-being of over 18,000 children who were born in the UK between 2000 and 2002. The most recent information was collected when they were seven years old. We identified children as having learning disabilities if they scored two standard deviations or more below average on tests of cognitive ability administered when aged seven (the standard approach for determining learning disabilities on the basis of cognitive testing). Some children were not tested at age seven because of learning disabilities. For these children we used test scores at age five and age three. The study also collects a wide range of information on child health, health behaviours (exercise) and exposure to common social determinants of poorer health (poverty, bullying).

Health Indicator	LD	No LD	OR/p
Child health rated by parent as 'fair' or 'poor'	10%	2%	4.67 (3.31-6.59)***
Parent report that child has had			
Eyesight problems	28%	17%	1.97 (1.59-2.45)***
Hearing problems	21%	13%	1.77 (1.39-2.26)***
Epilepsy	4%	1%	2.98 (1.93-4.62)***
Wheezing	35%	27%	1.42 (1.16-1.74)**
Asthma	19%	16%	1.23 (0.96-1.58)
Eczema	36%	37%	0.99 (0.81-1.21)
Hay fever	15%	16%	0.97 (0.74-1.27)
Two or more accidents requiring medical attention	9%	4%	2.18 (1.54-3.09)***
Been admitted to hospital	15%	9%	1.91 (1.45-2.51)***
Been admitted to hospital more than once	3%	1%	2.25 (1.21-4.21)**
Obese	9%	5%	1.72 (1.20-2.46)**
Scores in 'abnormal' range on the Strength & Difficulties Questionnaire ...			
Overall	34%	7%	6.79 (5.45-8.45)***
Conduct Difficulties	23%	9%	3.31 (2.61-4.20)***
Emotional Difficulties	18%	6%	3.29 (2.52-4.29)***
Hyperactivity	41%	11%	5.36 (4.36-6.59)***
Peer Problems	25%	7%	4.53 (3.58-5.72)***
Three or more of the above health problems	52%	28%	2.72 (2.22-3.33)***
Never does sport/exercise	56%	25%	3.77 (3.10-4.59)***
Lived in materially poor home at more than one age	44%	20%	3.26 (2.63-4.05)***
Bullied more than 'once or twice' at school	14%	6%	2.54 (1.91-3.37)***

Note, *** p<0.001, ** p<0.01

There were few differences between boys and girls in the increased risk for poor health. The exceptions were that: (1) girls (but not boys) with learning disabilities were at greater risk of obesity (13% of girls with learning disabilities were obese); (2) boys (but not girls) with learning disabilities were at greater risk of having multiple accidents (12% of boys with learning disabilities had had two or more accidents requiring medical attention).

The Health of Adolescents with Mild/Moderate Learning Disabilities

As little is known about the health of adolescents with learning disabilities, we extracted new evidence from the Longitudinal Study of Young People in England. Beginning in 2004, this study is tracking over 15,000 adolescents as they transition from mainstream school to adult life. 532 (3.5%) of the children had been identified through education records as being at School Action Plus or a having a Statement of SEN associated with *Moderate Learning Difficulty* (mild or moderate learning disabilities). The study also contains some limited information on child health, health behaviours (smoking) and exposure to common social determinants of poorer health (poverty, bullying).

Boys	Health Indicator	MLD	No MLD	OR/p
Age 13-14	Ever smoked	16%	9%	1.99 (1.45-2.72)***
	Poor (eligible for Free School Meals)	44%	16%	4.05 (3.24-5.06)***
	Bullied at school on at least a weekly basis	27%	13%	2.46 (1.90-3.18)***
Age 14-15	Health 'poor'	5%	2%	2.26 (1.26-4.05)**
	Possible mental health problem (GHQ 4+)	18%	12%	1.66 (1.19-2.32)**
	Smoked in last year	27%	17%	1.83 (1.37-2.44)***

Note, *** p<0.001, ** p<0.01

Boys with mild/moderate learning disabilities reported: significantly poorer self-rated health and mental health than their peers; at age 13/14 that they had ever smoked and at age 14/15 that they had smoked in the last year; and that they were more likely to be bullied on a weekly basis at school. They were also more likely to live in a poorer household.

Girls	Health Indicator	MLD	No MLD	OR/p
Age 13-14	Ever smoked	17%	15%	1.20 (0.78-1.84)
	Poor (eligible for Free School Meals)	46%	16%	4.31 (3.17-5.87)***
	Bullied at school on at least a weekly basis	33%	13%	3.34 (2.37-4.72)***
Age 14-15	Health 'poor'	4%	4%	1.14 (0.50-2.62)
	Possible mental health problem (GHQ 4+)	20%	25%	0.72 (0.46-1.12)
	Smoked in last year	21%	27%	0.73 (0.49-1.10)

Note, *** p<0.001, ** p<0.01

There were no statistically significant differences in health status or health behaviours between girls with and without mild/moderate learning disabilities. They were, however, more likely to be exposed to common social determinants of poorer health (poverty, bullying).

Across boys and girls with mild/moderate learning disabilities exposure to common social determinants of poorer health (poverty, bullying) at age 13/14 was associated with poorer health outcomes behaviours at age 14/15 (although these associations only reached statistical significance for poverty and smoking and bullying and mental health).

Emotional and Behavioural Difficulties

Bivariate analysis of data from the UK's Millennium Cohort Study demonstrated that three year old children with developmental delay have significantly higher rates of emotional and behavioural difficulties in comparison to their typically developing peers [151]. The new analyses presented above indicates that these differences are clearly apparent at age seven, with children with learning disabilities being over three times more likely to have conduct difficulties and emotional difficulties, over four times more likely to have difficulties relating to their peers and over five times more likely to have hyperactivity/ADHD. After controlling for the possible confounding effects of socio-economic status and area deprivation, there was still an association between cognitive performance and total difficulties and there were statistically significant differences between total difficulties, conduct difficulties, hyperactivity and peer problems in the developmentally disabled group compared to the control group [23, 151]. Recent research has suggested that Australian children with borderline learning disabilities were only more likely to show persistent conduct difficulties across childhood than their peers if exposed to environmental adversity [152]. Among children not exposed to environmental adversity at age 4 or 5, risk of persistent conduct difficulties was low, with no differences in rates between children with or without borderline learning disabilities. Among children exposed to multiple environmental adversities at age 4 or 5, risk of persistent conduct difficulties was much higher and particularly so among children with more severe learning disabilities.

Studies show that prevalence of depression is higher in adolescents with learning disability than in typically developing adolescents [153]. A literature review of risk factors for depression among adolescents with learning disability demonstrated that for specific groups, such as those with Down's syndrome, there is a biologically elevated risk of depression, while for other groups with learning disabilities the risks seem to be more often environmentally determined. Similarly, parental depression and family difficulties are risk factors for depression in children and studies have shown that parents of children with learning disabilities often experience increased levels of stress and higher rates of divorce and separation [153, 154].

Comorbid Conditions

Not only are the aforementioned conditions commonly associated with learning disability, but they are also commonly associated with each other. For example, increased rates of epilepsy, emotional disorders, conduct disorders and ASD have been reported among children with ADHD [155-159]. One study contrasted the comorbidity of challenging behaviours and ASD with challenging behaviours and learning disability [160]. On a questionnaire assessing challenging behaviours, 20% of typically developing children would be expected to have borderline or abnormal scores, indicating potential conduct disorders, while for a group of children with ID, 41.6-63.2% scored in the abnormal range and 63.8-87.5% of a group of children with ASD scored in the abnormal range [160]. After controlling for a number of potentially confounding variables (e.g., differences in socio-economic position), the presence of ASD and learning disabilities always significantly and independently increased the odds for challenging behaviour, with ASD having the greatest impact.

Common Behaviours among Young People with Impairments/Disabilities

A number of developmental and learning impairments are the result of particular syndromes and these conditions, in turn, are often accompanied by a certain behavioural phenotype [161]. For instance, children with Fragile-X syndrome often display high levels of escape-motivated problem behaviours [162]. Similarly, one study found that 96.9% of individuals with Smith-Magenis syndrome (SMS) displayed self-injurious behaviour, 87.5% displayed physical aggression, 81.3% displayed destructive behaviour and 43.8% were verbally aggressive[163]. Sleeping disturbances are frequently associated with a number of developmental conditions, such as epilepsy, Williams syndrome and Down's syndrome. In epilepsy, chronic sleep disturbances are thought to interfere with memory consolidation and healthy cognitive development [150]. Another study found that 97% of parents of children with Williams syndrome reported that their child had sleep difficulties and these disturbances could have negative impacts on daytime behaviour and learning; likewise, children with Down's syndrome were found to have significantly more difficulty with sleep, including bedtime resistance, night waking and sleep anxiety, with 78% of parents reporting that their child seemed tired during the day indicating inadequate sleep [164, 165].



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 (and possibly greater vulnerability when exposed) to well established 'social determinants' of poorer 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 and other service provision.

Evidence for these determinants of health inequalities is outlined below.

The 'Social Determinants' of Health

People with learning disabilities, especially people with less severe learning disabilities and people with learning disabilities who do not use learning disability services, 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, 166-172]. 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 [23, 152, 173]. Furthermore it has been shown that over time families with a child with a learning disability are more likely to be poor or become poor and are less likely to escape from being poor than other families [174]. 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 physical and mental health among British children and adolescents with learning disabilities [21-23]; (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 learning functioning [175]; (3) a significant proportion of increased rates of self-reported antisocial behavior among adolescents with learning disabilities [176]; 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 [151].

Exposure to bullying at school and overt discrimination in adulthood are both predictive of poorer general health among adults with learning disabilities [167]. Given the association between minority ethnic status and poverty and the exposure of people with learning disabilities from minority ethnic communities to overt racism [177], 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 and Environmental Factors

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities [89]. In addition a number of syndromes associated with learning disabilities are also associated with some specific health risks [61, 67, 178-185], 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 / 22q11.2 deletion, Williams syndrome, Lesch-Nyhan syndrome, Cri du Chat syndrome and Smith-Magenis syndrome;
- obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome, Down's syndrome and Bardet-Biedl syndrome;
- sleep problems are more prevalent among children with Williams Syndrome and Down's Syndrome [164, 165].

Recent research has highlighted the possible interactions between genetic and environmental determinants of poorer health. For example, genetically determined preferences may create motivational states that lead to the development of behaviours reinforced by environmental factors [186]. For example, individuals with Angelman syndrome often find social contact extremely pleasing and may come to display aggressive or self-injurious behaviours if these are effective in maintaining attention from carers. Similarly, dysfunction of the HPA-axis in people with Fragile-X syndrome can lead to anxiety in social situations resulting in the development of challenging behaviours [186].

It is also apparent that environmental conditions can increase the expression of genetically determined risk or that genetic factors and environmental factors may independently lead to the same health outcome. For example, ADHD appears to have a genetic component involving the regulation of dopamine and serotonin neurotransmitters in the brain (which can lead to problems with executive function control of impulsive behaviour); however, the antenatal environment can increase risk of ADHD if the foetus is exposed to alcohol or tobacco and the child-rearing environment can increase risk if the child has been exposed to trauma or neglect [157].

Communication & Health Literacy

People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses [187-189]. 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, carers may have difficulty in recognizing expressions of need, or the experience of pain, particularly if the person concerned does not communicate verbally [45, 70, 190]. Care workers may also feel that they do not have the knowledge, skills and training required to recognise emerging health problems or the resources to effectively promote health literacy [147, 191]. People with learning disabilities experience a lack of



knowledge and choice in relation to healthy eating [192]. People with learning disability express feelings of frustration that they are not listened to, treated unfairly and excluded from decision making about important aspects of their lives and care [193]. Information and support such as that related to breast cancer and mammography may not meet the needs of some people with learning disability [194].

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 [195]. Carers generally have a poor knowledge about public health recommendations on dietary intake [196].

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%) [195, 197-199]. People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity [195].

Obesity & Underweight

People with learning disabilities are much more likely to be either underweight or obese than the general population [20, 195, 197, 198, 200-202]. Women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity [195, 198, 201-203]. The high level of overweight status amongst people 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 [195, 204]. However, rates of smoking are considerably higher among adolescents with mild learning disability [205] and among people with learning disabilities who do not use learning disability services [172]. People with learning disabilities with identified substance misuse were more likely to be male (61%) and to misuse alcohol [206].

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 [207]. A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases [105]. High rates of unsafe sexual practices has been reported among gay men with learning disabilities [208].

Access to and the Quality of Healthcare and Other Services

Organisational barriers

A range of organisational barriers to accessing healthcare and other services have been identified [26, 27, 31, 69, 209-215]. These include:

- scarcity of appropriate services;
- physical barriers to access;
- eligibility criteria for accessing social care services;
- 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;
- lack of expertise and disablist attitudes among healthcare staff;
- 'diagnostic overshadowing' (e.g. 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).

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' [216]. In respect of the use of substitute (proxy) decision-making one study of residential care found that whilst there was general compliance with the Mental Capacity Act (2005) in relation to larger strategic decisions there was less compliance in respect of day-to-day decisions such as activity and food choices [217]. A recent study in Wales of health care professionals and social workers identified gaps in knowledge and training needs in relation to the Mental Capacity Act (2005) and similar findings were reported from a study of healthcare emergency workers in England [218, 219].

Transition

Transition between services has been reported as problematic for some people with learning disability; this may for example include transition from children's services to adult services, but equally could be transition between hospital services and home or community services, or transitions from one phase of education to another. One study of teenagers' transitions through health, social care and education services found weaknesses in transition planning, variable and mismatched eligibility criteria, lack of clarity from professionals and poor co-ordination between services together with low levels of satisfaction among family carers [220]. A study of local authorities in Wales found that transition protocols for post-secondary education or employment were often vague with some lacking specific information about how young people would be involved and often failed to clarify the role of other agencies such as health services in these transitions [221, 222].

Health Screening and Health Promotion

A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities [209, 210]. These include:

- Assessment for vision or hearing impairments; [223-225]
- Routine dental care; [43, 169, 212]
- Cervical smear tests; [226-228]
- Breast self- examinations and mammography; [194, 227, 229-231]

Access to health promotion may be significantly poorer for people with more severe learning disabilities [19] and people with learning disabilities who do not use learning disability services [172]. Staff in residential care homes had insufficient training and skills to effectively engage people with learning disabilities in health promotion activities and many did not have access to important relevant information such as a person's family history [191].

Primary Health Care

People with learning disabilities visit their GP with similar frequency to the general population [232-234]. However, given the evidence (above) 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 [235]. In a recent study mean consultation rates for adults with learning disability were found to be lower than for the general population; increased age, female gender and having a paid carer were associated with greater use of GP services [213].

Collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally regarded as poor [236]. Adults aged over 60 with learning disabilities are less likely to receive a range of health services compared to younger adults with learning disabilities [237].

A number of papers draw attention to the benefits of health screening to help identify unmet health needs [47, 225]. 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 [46]. However, at present less than 50% of adults who are eligible for health checks under an incentivised Directed Enhanced Service scheme receive them [238]. While providing financial incentives to GPs may influence practice, incentives should be tailored to the particular health needs of people with learning disabilities rather than being based solely on general population health needs [239]. Furthermore GP practices may experience difficulties in accurately identifying people with learning disabilities in order to offer them health checks and other services [240, 241].

In the UK and in other countries, adults with learning disabilities and especially adults who show challenging behaviours, are commonly prescribed anti-psychotic medication [110, 242-249]. Such a widespread 'off-label' use of anti-psychotic medication is of concern 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 [61].

Secondary Health Care

There are significant variations in NHS total expenditure and expenditure per person on specialist services for people with learning disabilities across different areas of England, with lower spending in rural areas [250] and significant variation in the services provided to people with learning disabilities by specialist NHS Trusts [251]. 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 [252]. A recent study found that people with learning disability living in areas which had higher levels of deprivation made less use of secondary outpatient care but more use of accident and emergency care than those living in less deprived areas [253].

People with learning disabilities with cancer are less likely to be informed of their diagnosis and prognosis, be given pain relief, be involved in decisions about their care and are less likely to receive palliative care [254-256]. In one study nursing staff in UK general hospitals were found to have less positive feelings towards people with learning disability than people with physical disability [257].

Concern has been expressed with regard to the availability of and access to mental health services by people with learning disabilities [258-260]. 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) [242, 246-248, 261, 262]. 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 [61].

Non-health services

Wellbeing, health and quality of life are influenced by services other than health services including for example social care, education, employment, housing, transport and leisure services; this may be especially true for people with learning disabilities who may be regular users of these services. Evidence of how these services impact on the health of people with learning disabilities in the UK is scarce and researchers are faced with a number of methodological difficulties.

For example a recent literature review of supported housing found that smaller housing units had benefits in terms of choice, self-determination and participation but identified no measurable benefits for physical health [263]. Whilst another review found evidence of better quality of life for people living in dispersed rather than clustered housing [264].

Similarly there is little recent research into the link between social care services and the health of people with learning disabilities; for example one review found no research into the role of social care staff in initiating or supporting access to annual health checks [265].

There is some recent evidence to suggest that supported employment can enhance the quality of life of some people with learning disabilities [266, 267]. However employment rates for people with learning disabilities in the UK remain low [268]. Furthermore a study of people in Scotland drew attention to negative effects on people's psychological wellbeing resulting from the breakdown of supported employment which occurred in 13 of 49 people studied [269].

We are not aware of any recent UK research which specifically measures the impact of leisure services, travel services or education services on the health of people with learning disabilities.

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 Equality Act 2010, the Mental Capacity Act 2005, the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and 2005 and the UN Convention on the Rights of Persons with Disabilities [25-30].

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 [28, 29, 33, 270].

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, 18].

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 [18, 271]. 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 [238, 272]. 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;
- enhancing healthcare workers' knowledge and improving their skills for working with 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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