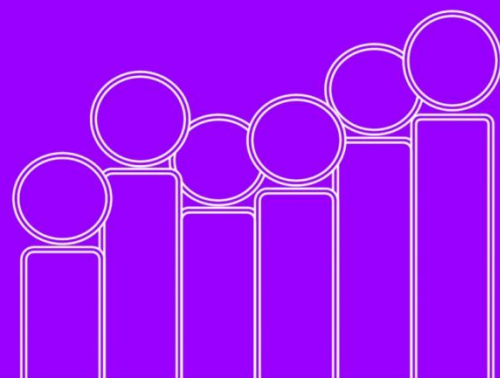




Improving Health and Lives:  
Learning Disabilities Observatory

# Health Inequalities & People with Learning Disabilities in the UK: 2012

Eric Emerson, Susannah Baines, Lindsay Allerton  
and Vicki Welch



*Supported by the Department of Health*



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IHAL 2012-11

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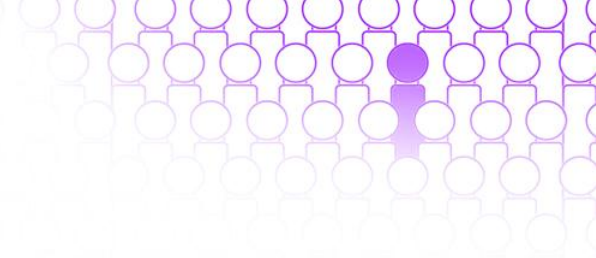
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## Acknowledgements

We would like to thank the members of our International Advisory Group who freely gave of their time to make helpful comments and suggestions on drafts of this and previous iterations of this report: Professor Sally Ann Cooper (University of Glasgow, Scotland), Associate Professor Robert Davis (Monash University, Australia), Professor David Felce (Cardiff University, Wales), Dr Gloria Krahn (Centre for Disease Control and Prevention, USA), Professor Nick Lennox (University of Queensland, Australia), Professor Gwynnyth Llewellyn (University of Sydney, Australia), and Associate Professor H el ene Ouellette-Kuntz (Queens University, Canada). Particular thanks to Professor Sally Ann Cooper for drawing our attention to the value of using the Dahlgren and Whitehead ‘rainbow’ to frame our discussion of the determinants of health inequalities.

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## Introduction

Learning disability refers to a significant general impairment in intellectual functioning that is acquired during childhood.<sup>1</sup> In England approximately 1.2 million people have learning disabilities.<sup>2</sup> It has been estimated that between 20% and 33% of people with learning disabilities known to local authorities also have an autistic spectrum disorder.<sup>3</sup> Recent research has suggested that 55% of children aged 10-14 who had a current diagnosis of an autistic spectrum disorder also had learning disabilities.<sup>4</sup>

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable.<sup>5-21</sup> As such, these differences represent health *inequalities*.<sup>22</sup>

The health inequalities faced by people with learning disabilities in the UK start early in life<sup>23-28</sup> and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care.<sup>29-37</sup> The inequalities evident in access to health care are likely to place many NHS Trusts in England in contravention of their legal responsibilities under the Equality Act 2010, the Mental Capacity Act 2005 and the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. They are also likely to be in contravention under international law of the UN Convention on the Rights of Persons with Disabilities,<sup>31</sup> and to fail to fulfil obligations following the signing by the UK of the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families<sup>38</sup> and the Rio Political Declaration on Social Determinants of Health.<sup>39</sup>

This is the third in a series of annual reports from the Learning Disabilities Public Health Observatory (LDPHO). In this series 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. The series builds on a previous 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 that was commissioned by the English Department of Health.<sup>14</sup> This was updated in our first LDPHO report in 2010<sup>40</sup> to include information published since 2002 and has since been updated on an annual basis.<sup>41</sup> 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. The 2011 edition included a special section on health inequalities experienced by children with learning disabilities, including new analyses of data extracted from the Millennium Cohort Study and the Longitudinal Study of Young People in England.<sup>41</sup> In this edition we include a special section on the health of people with learning disabilities and challenging behaviours.



## 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.<sup>42-44</sup> 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.<sup>45</sup> 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.<sup>46</sup> Potentially preventable causes of mortality that are relatively common and affect most groups of people with learning disabilities include aspirational pneumonia and seizures.<sup>44</sup> A Department of Health funded three year confidential inquiry into the premature deaths of people with learning disabilities (CIPLOD, <http://www.bris.ac.uk/cipold/>) is due to report its findings in early 2013.

### General Health Status

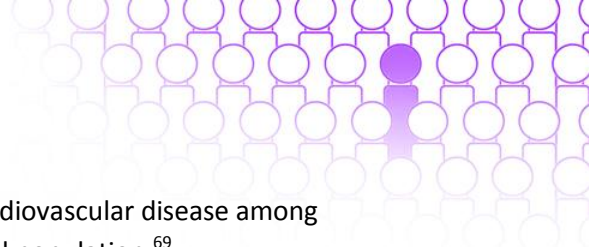
The risk of children being reported by their main carer (usually their mother) to have fair/poor general health is 2.5-4.5 times greater for children with learning disabilities when compared to their non-disabled peers.<sup>25 26</sup> One in seven adults with learning disabilities rate their general health as not good.<sup>47</sup> 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.<sup>48 49</sup> Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs.<sup>48 50-57</sup>

### 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).<sup>58-60</sup> However, the incidence and pattern of cancer amongst people with learning disabilities is rapidly changing due, in part, to increased longevity.<sup>58-61</sup> 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.<sup>62 63</sup> 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.<sup>64 65</sup> *Helicobacter pylori* antibody tests have indicated infection in 59% of residents of inpatient units for people with learning disabilities and 84% of those residents who had a history of being a long-stay resident (4 years or more) in hospital.<sup>66</sup>

### Coronary Heart Disease

Coronary heart disease is a leading cause of death amongst people with learning disabilities (14%-20%),<sup>42</sup> with rates expected to increase due to increased longevity and lifestyle changes associated with community living.<sup>67</sup> Almost half of all people with Down's syndrome are affected by congenital



heart defects.<sup>63 68</sup> It is unclear whether the overall prevalence of cardiovascular disease among people with learning disabilities differs from that seen in the general population.<sup>69</sup>

### **Respiratory Disease**

Respiratory disease is the leading cause of death for people with learning disabilities (46%-52%), with rates much higher than for the general population (15%-17%).<sup>42 45 65 70</sup> Recent data extracted from GP information systems in England indicate higher rates of asthma among adults with learning disabilities.<sup>71</sup> Increased rates of asthma among children with learning disabilities were reported in the special section on the health inequalities of children contained in the 2011 edition of this report.<sup>41</sup> 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.<sup>72</sup>

### **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%.<sup>73-75</sup> A marginally higher prevalence rate (22%) has been reported in an institutionalised population of adults with Down's syndrome.<sup>76</sup> A recent study has reported 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.<sup>77</sup> There is evidence that children with profound learning disabilities are at greater risk of experiencing short stature due to untreated growth hormone deficiency.<sup>78</sup>

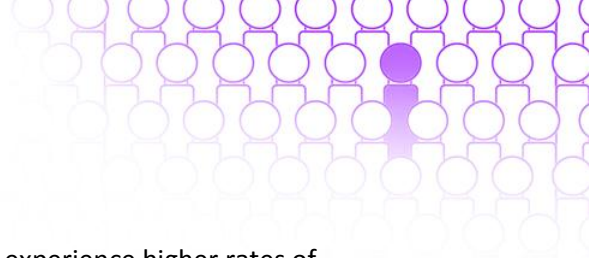
Increased rates of diabetes among adults with learning disabilities have been reported in population-based studies undertaken in the Netherlands and USA.<sup>79 80</sup> Recent data extracted from GP information systems in England also indicate higher rates of Type 1 and Type 2 diabetes.<sup>71</sup>

### **Physical Impairments**

Among adults with learning disabilities, being non-mobile has been associated with a sevenfold increase in annual mortality rates and being partially mobile has been associated with a twofold increase of death when compared with being fully mobile.<sup>46</sup> A population-based study in the Netherlands reported that people with learning disabilities are 14 times more likely to have musculoskeletal impairments.<sup>81</sup>

### **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.<sup>82-86</sup> 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.<sup>10</sup> 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 disabilities have a greater prevalence of some risk factors for osteoporosis than other people.<sup>87</sup>



## Injuries, Accidents and Falls

A recent UK study has reported that adults with learning disabilities experience higher rates of injuries and falls when compared to the general population.<sup>88</sup> Among people with learning disabilities in Assessment and Treatment Units, 22% experienced at least one accident in the last three months, and 2% experienced 10 or more accidents.<sup>89</sup> 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.<sup>90-94</sup> 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.<sup>10</sup>

## Sensory Impairments

People with learning disabilities are 8-200 times more likely to have a visual impairment compared to the general population.<sup>95,96</sup> 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, and many more adults with learning disabilities not known to services may have visual impairments or blindness.<sup>97</sup> 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.<sup>95,98</sup> Those living independently or with family are significantly less likely to have had a recent eye examination than those living with paid support staff.<sup>99</sup> Carers of people with learning disabilities frequently fail to identify sensory impairments, including cerebral visual impairment.<sup>52,100,101</sup> A recent pilot study working with opticians increased the numbers of people with learning disabilities coming forward for an eye check, with some people with learning disabilities aged between 40-60 having their first eye test.<sup>102</sup>

## Pain

There is an increased risk of acute and chronic pain among people with learning disabilities as a result of high rates of co-occurring health conditions and physical impairments.<sup>103,104</sup> In a recent study, 67% of people with learning disabilities asked about their health reported pain, and 18% said they did not tell people when they were in pain.<sup>105</sup> Higher rates of the experience of pain have been reported in studies of children with developmental disabilities.<sup>106,107</sup> When experiencing pain, children with developmental disabilities show poorer communication, daily living, social and motor skills.<sup>108</sup> A minority of people, including people with learning disabilities, have depressed pain responses.<sup>104,109</sup> Carers may have difficulty in recognizing expressions of need, or the experience of pain, particularly if the person concerned does not communicate verbally.<sup>52,110,111</sup>

## 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.<sup>71,112-114</sup> A Standardised Morbidity Ratio of 3.9 (95% CI 2.5–5.7) has been reported for adults with learning disabilities aged 65 years and over when compared to adults in the general population.<sup>115</sup> 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.<sup>116</sup> Amongst people with moderate to profound learning disabilities, deaths from dementia are more common in men than women,<sup>117</sup> however dementia itself has been found to be more common in women.<sup>118</sup>





## 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.<sup>71 119-123</sup> A recently published long term follow up study has indicated that the onset of epilepsy in people with autistic spectrum disorder may occur later than in both the general population and among people with learning disabilities without autism.<sup>124</sup>

Uncontrolled epilepsy can have serious negative consequences for both quality of life and mortality.<sup>125 126</sup> The relationship between epilepsy and mental health problems among people with learning disabilities is unclear; while one recent study has reported that people with epilepsy were less likely to have schizophrenia spectrum, anxiety and personality disorders,<sup>122</sup> another has reported that the one year incidence rate for commonly occurring psychiatric disorders was up to seven times higher for people with epilepsy.<sup>127</sup>

A recent review of English language published research found evidence of the misdiagnosis of epilepsy in people with learning disabilities, including both false positives and false negatives that may result in inappropriate treatment.<sup>128</sup> Anti-epilepsy medication is associated with a number of problems such as disturbed sleep for some people with learning disabilities.<sup>129</sup> A recent U.S study has suggested that some of the side effects of anti-epilepsy medication may be greater for people with learning disabilities.<sup>130</sup>

## Sleep Disorders


A recent systematic review reported estimated prevalence rates of sleep problems in adults with learning disabilities ranging from 9% to 34%, with an estimated prevalence of 9% being reported for significant sleep problems. Sleep problems were associated with the following factors: challenging behaviour; respiratory disease; visual impairment; psychiatric conditions; and using psychotropic, antiepileptic and/or antidepressant medication.<sup>131</sup>

## 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.<sup>27 132</sup> Increased prevalence of additional mental health disorders is particularly marked for people with autistic spectrum disorder (odds ratio (OR) 33.4), ADHD/hyperkinesia (OR 8.4) and conduct disorder (OR 5.7).<sup>27 132-134</sup>

Challenging behaviours (such as aggression, destruction and self-injury) are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49.<sup>135-141</sup> In a recent study self-injurious behaviour was recorded for 27% of individuals (children and adults) with learning disabilities, and the same study reported self-injurious behaviour for between 45% and 93% of people with certain genetic syndromes.<sup>142</sup> In some instances, challenging behaviours may result from pain associated with untreated medical disorders.<sup>111 136 143-145</sup>

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to general population rates.<sup>71 146-148</sup> 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.<sup>149</sup> 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.<sup>150-152</sup> Recent research has suggested that people with learning disabilities who live with their families are more likely to have anxiety disorders whilst those who live independently of their family are more likely to have personality disorders and overall higher rates of psychopathology.<sup>153</sup> Adults with learning disabilities 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.<sup>154</sup>

There is some evidence to suggest important gender differences in the mental health needs of adults with learning disabilities and autistic spectrum disorder,<sup>118</sup> and among men and women with learning disabilities more generally.<sup>155</sup> High rates of mental health problems have also been reported among mothers with learning disabilities.<sup>156</sup>

## Oral Health

One in three adults with learning disabilities and four out of five adults with Down's syndrome have unhealthy teeth and gums,<sup>50</sup> with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth.<sup>157 158</sup> 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.<sup>159</sup> A recent survey involving 387 adults with learning disabilities across 25 PCTs reported that participants with learning disabilities had higher rates of untreated decay, a greater number of extractions and were less likely to have posterior functional contacts than adults in the general population.<sup>160</sup>

## Dysphagia

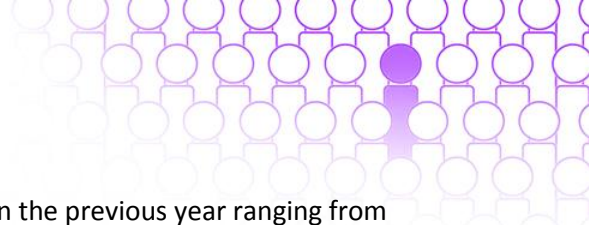
Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. Dysphagia may affect 8% of adults known to learning disability services.<sup>161</sup> More recent research has estimated that 15% of adults known to specialist learning disability services require mealtime support. Reasons for support include difficulty swallowing, poor motor co-ordination, risky eating or drinking behaviours, and slow eating or food refusal.<sup>162</sup> Forty per cent of those with learning disabilities and dysphagia experience recurrent respiratory tract infections; other negative health consequences include asphyxia, dehydration and poor nutritional status.<sup>161 163</sup>

## Gastro-Oesophageal Reflux Disease (GORD)

GORD causes pain and may contribute to sleep disturbance, problem behaviour, anaemia and risk of oesophageal cancer.<sup>10</sup> High rates of GORD (approximately 50%) have been reported in international studies.<sup>164 165</sup> 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 international studies.<sup>165 166</sup> 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.<sup>167</sup> People with learning disabilities 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.<sup>168</sup>

## 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.<sup>169</sup> Parents and carers often feel that women with learning disabilities will not cope well with menstruation, and in these circumstances they may seek medical help to suppress or eliminate periods using medication, hormonal intrauterine devices or various forms of surgery.<sup>170 171</sup> 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.<sup>170</sup> Conversely a number of authors conclude that with support and appropriate education most women with learning disabilities can manage their own menstrual care.<sup>172 173</sup>

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.<sup>174 175</sup> Evidence also suggests that women with learning disabilities are not given sufficient information or are not fully involved in decisions about contraception.<sup>174 176 177</sup> Furthermore there is evidence that women are prescribed contraception even when they are not sexually active or are past child bearing age.<sup>174</sup> A small UK study has reported that none of the women with learning disabilities who had been sterilized for contraceptive purposes were sexually active during a 20 year follow up period.<sup>178</sup>

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.<sup>179 180</sup> A recent UK study reported that women with learning disabilities had similar experiences of menopausal symptoms to other women but that they had poorer understanding of menopause and menstruation.<sup>181</sup> The same authors note elsewhere that carers report being poorly trained and resourced to help women understand the menopause.<sup>182</sup> An Australian study has reported that women with learning disabilities had greater risk of adverse pregnancy and birth outcomes including greater rates of pre-eclampsia and low birth weight.<sup>183</sup>

## Determinants of Health Inequalities

The influences on (or determinants of) health are complex, ranging from the influence of a person's genetic inheritance through to the social conditions into which we are born, grow up in and live out our lives. One of the most influential frameworks for summarising these influences is the 'rainbow model' developed by Göran Dahlgren and Margaret Whitehead in 1991 (Figure 1).<sup>184</sup>



**Figure 1:** The Dahlgren/Whitehead 'Rainbow' Model of the Determinants of Health (and Health Inequalities).

The model draws attention to the range of factors that shape our health, and also the interconnectedness between different 'layers' of the rainbow. So, for example, the general socio-economic, cultural and environmental conditions of any given society will have a profound impact on the living and working conditions experienced by particular groups of people in that society. Similarly, these broader 'social determinants' of health along with constitutional factors and social and community networks will shape individual lifestyle factors that are important for health (e.g., exercise, nutrition, smoking and drug use). We will use this model in this report to structure our consideration of the determinants of the health of (and health inequalities experienced by) people with learning disabilities.

## General Socio-Economic, Cultural and Environmental Conditions

Prevailing socio-economic, cultural and environmental conditions in the UK have a profound impact on shaping the material and psychosocial characteristics of our living conditions. They influence the types and quantity of food we can access, our risk of exposure to infectious diseases, the education we receive, the type and quality of housing we can afford, the types of employment that may be available to us, our opportunities for leisure activities, our security and safety, our access to social networks and to timely and effective health care. There are, however, some stark inequalities within the UK with regard to the ability of different groups in society (e.g., people living in poverty, people from some minority ethnic communities, people with disabilities) to access the types of living conditions that promote positive health.<sup>22 185-189</sup>


Of particular relevance to understanding the health inequalities experienced by people with learning disabilities is the extent to which the discriminatory cultural and social attitudes toward disability embedded in our social institutions serve to restrict the access of disabled people to living conditions that are associated with better health (e.g., better education; wealth; autonomy and power; better quality housing; secure and rewarding employment; access to timely and effective health care).<sup>5 21 190-194</sup> It is as a result of the growing awareness of the impact of discriminatory socio-cultural practices in constraining the life experiences of people with disabilities that disability itself is being increasingly seen as a human rights issue.<sup>194-199</sup> As recently argued by the World Health Organization and World Bank, '*disability is a human rights issue because:*

- People with disabilities experience inequalities – for example, when they are denied equal access to health care, employment, education, or political participation because of their disability.
- People with disabilities are subject to violations of dignity – for example, when they are subjected to violence, abuse, prejudice, or disrespect because of their disability.
- Some people with disability are denied autonomy – for example, when they are subjected to involuntary sterilization, or when they are confined in institutions against their will, or when they are regarded as legally incompetent because of their disability.<sup>195</sup>

The need to address the discrimination faced by people with disabilities (and the disablist attitudes and practices that give rise to such discrimination) has been highlighted in numerous reports, UK legislation (e.g., 1995 and 2005 Disability Discrimination Acts, 2010 Equality Act) and the development (and ratification by the UK) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>197</sup>

- Disablism refers to '*the social beliefs and actions that oppress/exclude/disadvantage people with impairments*' and includes consideration of the overt and systemic (or institutional) discrimination faced by people with certain health conditions or impairments.<sup>200</sup>
- Article 2 of the UNCRPD defines discrimination on the basis of disability as '*... any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.*'



- 
- In the landmark report *Death by Indifference*, Mencap defined institutional discrimination in the following terms: ‘... institutional discrimination results when organisations fail to make changes in the way they deliver their services to take into account people’s differing needs. Nor does the organisation deal with ignorance and prejudice within the workforce and culture of the organisation. We believe that there is a fundamental lack of understanding and respect towards people with a learning disability and their families and carers. This lack of understanding and respect leads to – and is demonstrated by – the poor design of systems, policies and procedures to meet the particular and differing needs of patients with a learning disability.’<sup>29</sup>

## Living and Working Conditions

The Department of Work and Pensions, through its *Fulfilling Potential* initiative,<sup>192 201</sup> is currently reviewing progress made and setting future priorities to support the full and equal participation of disabled people in contemporary UK society.<sup>192 201</sup> One component of this initiative, *Fulfilling Potential: Building Understanding*<sup>189</sup>, involves summarising and collating existing evidence on the wellbeing and life chances of disabled people. It is expected that the results of this exercise will be published in late 2012 or early 2013. In the section below, we summarise existing UK evidence on the extent to which people with learning disabilities have access to the 'living and working conditions' that promote better health.


### Exposure to Social and Environmental Adversities

As indicated in the previous section, people with learning disabilities are more likely than their non-disabled peers to be exposed to a range of 'social determinants' of poorer health. These include poverty, poor housing conditions, unemployment, social exclusion, violence and exposure to overt acts of abuse, victimisation and discrimination.<sup>5 9 21 189 195 202-210</sup> For example:

- English children with Special Educational Needs (SEN) associated with learning disabilities are twice as likely as their peers to live in poor households;<sup>210</sup>
- Over time families with a child with learning disabilities are more likely to be poor or become poor and are less likely to escape from being poor than other families;<sup>211</sup>
- In 2003/4 27% of 13-14 year-old adolescents with mild to moderate learning disabilities who were attending mainstream school reported being bullied at least weekly (compared to 13% of children without SEN);<sup>41</sup>
- In 2003/4 only 17% of working age adults with learning disabilities had a paid job, compared to 67% of men and 53% of women in the general population;<sup>203</sup>
- Local Authority returns for 2010/11 indicated that 6.6% of working age adults with learning disabilities were in any form of paid employment, with just 1.6% of men and 0.4% of women working for 30 or more hours per week;<sup>2</sup>
- In 2009/11 British adults with self-reported impairments of learning or understanding were nearly three times more likely than their non-disabled peers to have been a victim of violent crime over the last year and nearly seven times more likely to have been a victim of hate crime.<sup>209</sup>

This increased risk of exposure to environmental adversities among people with learning disabilities is the result of a number of different factors which vary in their importance across the life course.<sup>5 21</sup> These include:

1. Exposure to some adversities (e.g., child poverty) is known to impair cognitive development and will consequently increase the risk of the development of learning disabilities;<sup>212-215</sup>
2. As described in the preceding section, discrimination experienced by people with learning disabilities is likely to constrain their life opportunities and increase the risk of exposure to incidents of overt discrimination and abuse (e.g., unemployment, bullying, hate crime);
3. Some parental/family factors (e.g., low parental intelligence, maternal alcohol abuse) may be associated with both increasing the risk of their children developing learning disabilities and of becoming poor.



Whatever the underlying reasons, exposure to these types of adversities is predictive of poorer general health among people with learning disabilities, with the strength of the association appearing to be at least as strong as it is among the general population.<sup>25-28 202 216-220</sup> As such, it would be expected that people with learning disabilities would have poorer health, not because of their learning disability *per se* but because they are more likely than their non-disabled peers to be exposed to a range of ‘social determinants’ of poorer health. Indeed, it has been estimated that increased exposure to low socio-economic position/poverty may account for:

- 20–50% of the increased risk for poorer physical and mental health among British children and adolescents with learning disabilities;<sup>25-27</sup>
- 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;<sup>28</sup>
- a significant proportion of increased rates of self-reported antisocial behavior among adolescents with learning disabilities;<sup>218 219</sup> and
- 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.<sup>217</sup>

Given the association between minority ethnic status and poverty and the exposure of people with learning disabilities from minority ethnic communities to overt racism,<sup>221 222</sup> 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.

### **Access to and the Quality of Healthcare and Other Services**

Considerable attention has been drawn over the last decade to the importance of inequalities in relation to one key aspect of general ‘living and working conditions’; timely access to appropriate and effective health care. Inequalities in this area have been the focus of attention by the Disability Rights Commission,<sup>31</sup> Sir Jonathan Michael’s independent inquiry into the healthcare of people with learning disabilities,<sup>30</sup> the Parliamentary, Health Services and Local Government Ombudsman,<sup>34</sup> the House of Lords and House of Commons Joint Committee on Human Rights,<sup>194</sup> the Department of Health<sup>32 223-226</sup>, the Care Quality Commission<sup>227</sup> and Mencap.<sup>29 36</sup>

As noted above, in their landmark report *Death by Indifference* Mencap argued that the systemic failure of health care organisations to adjust their practices to take account of the particular needs and circumstances of people with learning disabilities should be considered as an example of institutional discrimination.<sup>29</sup> The continuing presence of inequalities in access to health care is likely to place many NHS Trusts in England in contravention of their legal responsibilities under the Equality Act 2010, the Mental Capacity Act 2005 and the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010.

A range of barriers to accessing healthcare and other services have been identified.<sup>30 31 35 37 144 228-235</sup> These include:

- scarcity of appropriate services;
- physical and informational barriers to access;
- unhelpful, inexperienced or discriminatory healthcare staff;



- increasingly stringent eligibility criteria for accessing social care services;
- failure of health care providers to make ‘reasonable adjustments’ in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- ‘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).

Concerns have also been expressed about the appropriate application of the Mental Capacity Act (2005) and other ‘safeguarding’ procedures in health care settings.<sup>227</sup> The National Patient Safety Agency, for example, reported concern about ‘consent being sought from a carer rather than taking the time to gain consent from the person with the learning disability’.<sup>236</sup> Research studies have highlighted low levels of compliance with the Mental Capacity Act in day-to-day decision making and food choices,<sup>237</sup> and gaps in knowledge and training needs among front line and professional staff in relation to the Mental Capacity Act (2005).<sup>238 239</sup>

The exposure by the BBC Panorama team of the degrading abuse of people with learning disabilities at Winterbourne View has highlighted once again the risks faced by people with learning disabilities (and especially those who also show ‘challenging behaviour’) when detained in institutional settings.<sup>89 136 227 240-245</sup> Concerns have also been raised about the inappropriate medical treatment of people with learning disabilities with ‘challenging behaviour’. In the UK and in other countries, for example, adults with learning disabilities (and especially those who show challenging behaviour) are commonly prescribed anti-psychotic medication.<sup>79 246-254</sup> 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.<sup>136 240 254</sup>

In the following sections we summarise knowledge about inequalities in access to: health screening and health promotion; primary health care; secondary health care; and non-health services.

### Health Screening and Health Promotion

A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities.<sup>228 229</sup> These include:

- Assessment for vision or hearing impairments;<sup>255-257</sup>
- Routine dental care,<sup>50 203 231</sup>
- Cervical smear tests;<sup>71 258-261</sup>
- Breast self- examinations and mammography;<sup>71 259 261-265</sup>
- Bowel and prostate screening.<sup>261</sup>

Access to health promotion may be significantly poorer for people with more severe learning disabilities<sup>23</sup> and people with learning disabilities who do not use learning disability services.<sup>205</sup> 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.<sup>266</sup> This is supported by a recent study which concluded that whilst people with learning disabilities can learn about their health through health promotion, to maintain their learning they need continued support from people other than health professionals, such as carers, families or community supports.<sup>267</sup>

## Primary Health Care

People with learning disabilities visit their GP with similar frequency to the general population.<sup>268-270</sup> 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.<sup>271</sup> In a recent study mean consultation rates for adults with learning disabilities 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.<sup>232</sup>


Collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally regarded as poor.<sup>272</sup> Adults aged over 60 with learning disabilities are less likely to receive a range of health services compared to younger adults with learning disabilities.<sup>273</sup>

A number of papers draw attention to the benefits of health screening to help identify unmet health needs.<sup>54-57 257</sup> 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.<sup>53</sup> However, at present only 53% of adults who are eligible for health checks under an incentivised Directed Enhanced Service scheme receive them.<sup>274</sup> 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.<sup>275</sup> Furthermore GP practices may experience difficulties in accurately identifying people with learning disabilities in order to offer them health checks and other services.<sup>276 277</sup>

## Secondary Health Care

The Care Quality Commission report that services for people with learning disabilities, people with mental health problems and people with substance abuse (and especially those provided by independent sector organisations) are performing more poorly than other sectors of health care.<sup>227</sup> The exposure by the BBC Panorama team of the degrading abuse of people with learning disabilities at Winterbourne View has highlighted once again the risks faced by people with learning disabilities (and especially those who also show 'challenging behaviour') when detained in institutional settings.<sup>89 136 227 240-245 278</sup>

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<sup>279</sup> and significant variation in the services provided to people with learning disabilities by specialist NHS Trusts.<sup>280</sup> 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.<sup>281</sup> A recent study has reported that people with learning disabilities 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.<sup>282</sup>



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.<sup>283-285</sup> In one study nursing staff in UK general hospitals were found to have less positive feelings towards people with learning disabilities than people with physical disabilities.<sup>286</sup>

Concern has been expressed with regard to the availability of and access to mental health services by people with learning disabilities.<sup>287-289</sup> 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).<sup>246 250-252 290 291</sup> 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.<sup>136</sup> In a recent study almost half of a clinical sample of people with severe/profound intellectual disabilities were being prescribed antipsychotics for challenging behaviour rather than any concomitant mental illness.<sup>292</sup>

### **Non-health services**

Wellbeing, health and quality of life are influenced by services other than health services including 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. Unfortunately, evidence of how these services impact on the health of people with learning disabilities in the UK is scarce. Evidence does suggest, however, that non-health services are important determinants of the general quality of life or wellbeing of people with learning disabilities.

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.<sup>293</sup> Another review found evidence of better quality of life for people living in dispersed rather than clustered housing.<sup>294</sup> 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.<sup>295</sup>

There is some recent evidence to suggest that supported employment can enhance the quality of life of some people with learning disabilities.<sup>296 297</sup> However employment rates for people with learning disabilities in the UK remain low.<sup>298</sup> 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 26% of participants.<sup>299</sup>

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.

Transition between services has been reported as problematic for some people with learning disabilities; 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.<sup>300</sup> 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.<sup>301 302</sup>

## Social & Community Networks

There is extensive evidence to suggest that people who have more extensive and closer social networks and people who report feeling connected to their local community tend to have better health.<sup>303-306</sup> Similar associations have been reported for people with learning disabilities, particularly in relation to the extent of contact with friends with learning disabilities.<sup>47 203 307-310</sup> It is of concern, therefore, that people with learning disabilities in the UK: have more restricted social networks than their non-disabled peers;<sup>203 308 309</sup> and are more likely to be socially excluded as a result of disablist attitudes and practices and being placed in educational and residential services geographically distant from their home communities.<sup>278 311 312</sup>

For example, results from the 2003/4 national survey of the life experiences of adults with learning disabilities in England indicated that:<sup>203</sup>

- 58% of adults with learning disabilities had infrequent contact with their families (compared to just 9% of adults without learning disabilities);
- 31% of adults with learning disabilities had no contact with friends (compared to just 3% of adults without learning disabilities);
- The most commonly reported barriers to having more social contact were:
  - Living too far away or problems with travelling (44%)
  - Not enough time (21%)
  - Lack of money (13%)
  - Not always enough support (11%)
  - Cannot get out or too ill (4%)
  - Afraid of going out (4%)

## Individual Lifestyle Factors

### Diet

Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables.<sup>313</sup> Carers generally have a poor knowledge about public health recommendations on dietary intake.<sup>314</sup>

### 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%).<sup>313 315-317</sup> People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity.<sup>313</sup> In a recent study about carer intentions, only 56% of care staff planned to encourage physical activity in those they support.<sup>318</sup>

### Obesity & Underweight

People with learning disabilities are much more likely to be either underweight or obese than the general population.<sup>24 71 313 315 316 319-321</sup> Women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity.<sup>313 316 320-322</sup> The high level of overweight status amongst people with learning disabilities is likely to be associated with an increased risk of diabetes.<sup>10</sup>

### Substance Use

Fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population.<sup>71 313 323</sup> However, rates of smoking are considerably higher among adolescents with mild learning disabilities<sup>324</sup> and among people with learning disabilities who do not use learning disability services.<sup>205</sup> People with learning disabilities with identified substance misuse were more likely to be male (61%) and to misuse alcohol.<sup>325</sup>

### 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.<sup>326</sup> A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases.<sup>81</sup>

## Constitutional Factors

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities.<sup>117</sup> In addition a number of syndromes associated with learning disabilities are also associated with some specific health risks;<sup>136 142 152 327-335</sup> for example:

- congenital heart disease is more prevalent among people with Down's syndrome and Williams syndrome;
- early onset dementia and immune system disorders are more common in people with Down's syndrome;<sup>335</sup>
- 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.<sup>336 337</sup>

In addition, approximately 33% of adults with severe or profound learning disabilities and 60-65% of children have difficulties of urinary incontinence and 25% have difficulties of bowel incontinence, difficulties that without effective management are associated with additional health risks.<sup>139 338</sup>

People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses.<sup>104 109 339</sup> 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.<sup>52 110 111</sup> In a recent study, 67% of people with learning disabilities asked about their health reported pain, and 18% said they did not tell people when they were in pain.<sup>105</sup>

With regard to health literacy care workers may 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.<sup>182 266</sup> People with learning disabilities experience a lack of knowledge and choice in relation to healthy eating.<sup>340</sup> People with learning disabilities express feelings of frustration that they are not listened to, are treated unfairly and are excluded from decision making about important aspects of their lives and care.<sup>341</sup> Information and support such as that related to breast cancer and mammography may not meet the needs of some people with learning disabilities.<sup>265</sup>





## The Health of People with Challenging Behaviour

The wellbeing of people with learning disabilities who show challenging behaviours has attracted increasing attention following the investigation of serious abuse at Winterbourne View.<sup>241-243 245</sup> In this special section of the report we summarise what is known about the physical and mental health of people with learning disabilities who show challenging behaviours.

### The Health Status of People with Challenging Behaviour

A number of studies have examined the extent to which the presence of health conditions increases the risk of a person showing challenging behaviours. The results of these studies indicate that the overall prevalence of challenging behaviours is greater among people with learning disabilities who:

- have additional impairments of vision or hearing;<sup>138 342</sup>
- are reported to have periods of disturbed sleep;<sup>342</sup>
- have mental health problems.<sup>343-347</sup>

Self-injury is markedly more prevalent among people with severe intellectual disabilities who also have significant impairments of mobility.<sup>342 348</sup>

Other studies have asked a slightly different question; are variations in the occurrence of challenging behaviours associated with variations in (underlying) health conditions? The results of these studies indicate that challenging behaviours are more likely to occur when the person:

- has an illness or pain including pain associated with gastroesophageal reflux, otitis media and constipation;<sup>347 349-355</sup>
- allergies;<sup>353 354</sup>
- has disturbed sleep;<sup>353 354 356 357</sup>
- is suffering from the side effects of medications.<sup>358 359</sup>

The conclusion that can be drawn from these bodies of research is that people with learning disabilities and challenging behaviours are more likely than people with learning disabilities without challenging behaviours to experience a range of health conditions or impairments. However, no population-based studies have directly examined the differences in health status between people with learning disabilities who do and do not show challenging behaviours. In the following panel we have extracted data from the UK's Millennium Cohort Study on the prevalence of health conditions and impairments among two groups of seven year children: children with learning disabilities and challenging behaviours; and children with learning disabilities who do not have challenging behaviours.



## The Health of Children with Learning Disabilities and Challenging Behaviour

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. We identified children as showing challenging behaviours if they scored in the borderline or abnormal range on the conduct difficulties subscale of the Strengths and Difficulties Questionnaire. 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	CB	No CB	OR/p
<b>Child health rated by parent as 'fair' or 'poor'</b>	17%	3%	6.92*** (3.00-15.96)
<b>Parent report that child has had</b>			
<b>Eyesight problems</b>	25%	30%	0.79 (0.52-1.21)
<b>Hearing problems</b>	24%	17%	1.51 (0.95-2.39)
<b>Epilepsy</b>	9%	4%	2.37* (1.08-5.23)
<b>Wheezing</b>	40%	30%	1.56* (1.05-2.30)
<b>Asthma</b>	27%	12%	2.65*** (1.61-4.36)
<b>Eczema</b>	33%	38%	0.80 (0.54-1.18)
<b>Hay fever</b>	15%	16%	0.95 (0.56-1.60)
<b>Two or more accidents requiring medical attention</b>	10%	5%	2.00 (0.98-4.11)
<b>Been admitted to hospital</b>	17%	13%	1.40 (0.83-2.35)
<b>Been admitted to hospital more than once</b>	4%	1%	3.22 (0.84-12.31)
<b>Overweight or Obese</b>	25%	23%	1.08 (0.69-1.70)
<b>3+ health problems</b>	32%	21%	1.79* (1.15-2.79)
<b>Never does sport/exercise</b>	67%	47%	2.32*** (1.57-3.41)
<b>Lived in materially poor home at more than one age</b>	61%	36%	2.77*** (1.81-4.25)
<b>Bullied more than 'once or twice' at school</b>	21%	10%	2.34** (1.36-4.03)

Note, \*\*\* p<0.001, \*\* p<0.01, \* p<0.05

For 13 of the 16 health indicators, children with learning disabilities and challenging behaviours had poorer health (or greater exposure to risk for poor health) than children with learning disabilities who did not have challenging behaviours. On eight indicators, these differences were statistically significant.



## The Determinants of the Poorer Health Status of People with Challenging Behaviour

The link between poor health and challenging behaviours is complex, involving three causal pathways.

- Health conditions or impairments may increase the risk of a person developing challenging behaviours;
- Challenging behaviours may increase the risk of a person developing health conditions or impairments;
- Other factors (e.g., exposure to adversity) may increase the risk of a person developing challenging behaviours and (independently) of developing health conditions or impairments.

Addressing the poorer health of people with learning disabilities who show challenging behaviours will require addressing each of these three pathways.

### Poor Health May Increase the Risk of Challenging Behaviour

Much challenging behaviour appears to represent the attempt by people with learning disabilities to exert some degree of control over important aspects of their day to day life (e.g., avoiding or escaping from events or activities they find distressing).<sup>136</sup> Physical and sensory impairments may additionally restrict the opportunities of people with learning disabilities to exert control over important aspects of their lives through non-challenging means. In addition, the experience of pain or illness may lower a person's tolerance for certain activities or events. If their only effective way of avoiding or escaping from events or activities they find distressing is through challenging behaviours, then the experience of pain or illness may evoke episodes of challenging behaviours.

### Challenging Behaviour May Increase the Risk of Poor Health

The physical acts associated with severe challenging behaviour may directly increase the risk of poor health. Most obviously, severe self-injurious behaviours can result in damage to the person's health through secondary infections, malformation of the sites of repeated injury through the development of calcified haematomas, loss of sight or hearing, additional neurological impairments and even death.<sup>136</sup> Serious aggression may result in significant injury to the person themselves as a result of the defensive or restraining action of others.<sup>360-363</sup>

However, the health consequences of challenging behaviours go far beyond their immediate physical impact. Indeed, the combined responses of the public, carers, care staff and service agencies to people who show challenging behaviours may prove significantly more detrimental to their health and wellbeing than the immediate physical consequences of the challenging behaviours themselves. Social responses that are likely to have an adverse effect on health include abuse, inappropriate treatment, social exclusion, deprivation and systematic neglect.

- *Abuse*: Challenging behaviour has been identified as a major predictor of abuse in North American institutional settings.<sup>364 365</sup> In the UK, recent analyses of the *Count Me In Census* indicated that in the previous three months 35% of people with learning disabilities in Assessment and Treatment Units had been assaulted, and 6% had been subject to 10 or more assaults.<sup>89</sup>

- *Inappropriate Treatment:* Studies undertaken in North America and the UK suggest that approximately one in two people with severe intellectual disabilities who show challenging behaviours are prescribed long-term anti-psychotic medication.<sup>249-252 366</sup> The widespread use of anti-psychotic medication raises a number 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 including weight gain and constipation; and (3) the use of anti-psychotics can be substantially reduced through peer review processes with no apparent negative effects for the majority of participants.<sup>254 367-369</sup> The use of mechanical restraints and protective devices to manage self-injury also gives cause for serious concern. Such procedures can lead to muscular atrophy, demineralisation of bones and shortening of tendons as well as resulting in other injuries during the process of the restraints being applied.<sup>360 370</sup>
- *Social Exclusion, Deprivation and Systematic Neglect:* Challenging behaviours have been associated, among other factors, with families' decisions to seek an out-of-home residential placement for their son or daughter.<sup>371 372</sup> Children and adults with challenging behaviours are significantly more likely to be excluded from community-based services and to be admitted, re-admitted to or retained in more remote and more institutional settings.<sup>247 248 278</sup>  
<sup>373</sup> Within community-based settings, challenging behaviours may serve to limit the development of social relationships, reduce opportunities to participate in community-based activities and employment, and prevent access to health and social services.<sup>308 374-378</sup>

#### **Other Factors May Increase the Risk of Poor Health and Challenging Behaviour**

The association between challenging behaviours and poor health may also reflect the operation of additional factors. For example, exposure to adversity in childhood (e.g., poverty, bullying) has been shown to have an adverse impact on both physical and mental/behavioural health.<sup>206</sup> In the panel above, nearly two out of three children who showed challenging behaviours had been exposed to repeated material adversity by age five years, putting them at significantly increased risk of poor health.

## 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 international obligations under the UN Convention on the Rights of Persons with Disabilities,<sup>29-34</sup> the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families<sup>38</sup> and the Rio Political Declaration on Social Determinants of Health.<sup>39</sup>

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.<sup>32 33 379 380</sup>

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.<sup>5 9 22</sup>


This report 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.<sup>22 381</sup>

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.<sup>274 382 383</sup> 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;<sup>384 385</sup>
- enhancing healthcare workers' knowledge and improving their skills for working with people with learning disabilities;<sup>386</sup>
- 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 frameworks of the Equality Act 2010 and the Mental Capacity Act 2005 (e.g., through providing more accessible information and longer appointment times);<sup>386-388</sup>

- 
- building a more robust evidence-base of the determinants of health inequalities and the effectiveness of interventions to reduce health inequalities experienced by people with learning disabilities. For example, existing clinical guidelines relating to areas of health inequality for people with learning disabilities rarely contain content relevant to people with learning disabilities,<sup>389</sup> an omission at least in part due to under investment in high quality research on the health of people with learning disabilities;
  - monitoring progress towards the elimination of health inequalities faced by people with learning disabilities.

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