

The picture for people with a learning disability

Historically, people with a learning disability have experienced worse health than the general population. Their health needs have been poorly understood and inadequately met. How well healthcare services can understand and meet the needs of these people, and improve their health, is a key test of their ability to care for the population as a whole.

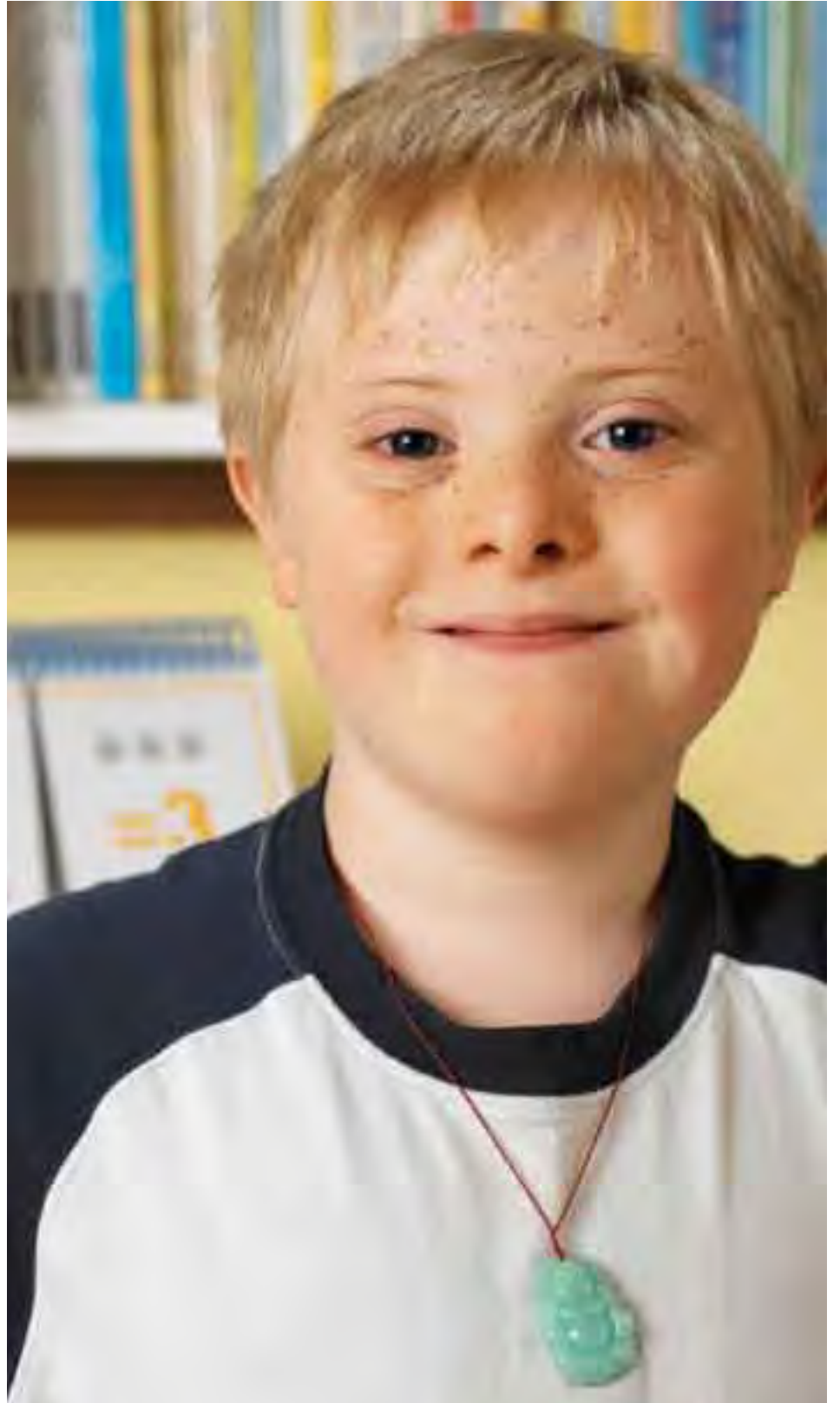
Main points at a glance

- We have concerns about the commissioning of health services for people with learning disability. We are carrying out further work in this area and will report on this in 2009.
- Specialist healthcare services for people with learning disabilities are generally safe. However, they do not always adequately meet the wider needs of the people using them.
- There are still barriers for people with a learning disability in getting access to mainstream services, and so their physical health needs are too often poorly addressed. Within mainstream services, staff lack an awareness of how to respond to someone with a learning disability.
- We have too little information about care for people with both a learning disability and mental health needs, but we have concerns and so we have included in the annual health check for 2008/09 a measure of performance in this area.

‘People with a learning disability’ is a broad term, and a short way of referring to people who have a significantly reduced ability to understand new or complex information and learn new skills, and a reduced ability to cope independently, which started before adulthood with a lasting effect on development.¹⁸⁷

In this report and to avoid confusion, we use the term ‘learning disability’, as this is the one most commonly used in healthcare.





Learning disability

6 pictures of healthcare

We acknowledge that 'learning difficulty' is often preferred, particularly by users of these services, but this is also used in education where it has a different meaning.

Facts and figures

We do not know exactly how many people with learning disabilities are living in England and Wales. Recent estimates suggest that 985,000 people in England have a learning disability (2% of the general population) including 828,000 people aged 18 or over. Of these, it is thought that 177,000 are known users of learning disability services, most of whom will have severe or profound learning disabilities.¹⁸⁸ Department of Health estimates for adults with severe or profound learning disabilities put the figure at 145,000. There are thought to be approximately 60,000 people with a learning disability in Wales.¹⁸⁹

These numbers are expected to rise considerably over the next two decades, because of increased life expectancy, and growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood.

Prevalence is higher in South Asian communities.¹⁹⁰ People with learning disabilities from minority ethnic communities can experience disadvantage due to both race and impairment.

People with learning disabilities tend to experience worse health, have greater need of healthcare and are more at risk of dying early compared with other people – they are 58 times more likely to die before the age of 50.¹⁹¹ Specifically, they are more likely to:

- Die from things that could have been prevented. Four times as many people with learning disabilities die of preventable causes as people in the general population.

- Have epilepsy. A rate of 22% has been estimated, compared with 0.4% to 1% in the general population.
- Be at risk from a thyroid dysfunction, particularly hypothyroidism.
- Have a sensory impairment. People with learning disabilities are between 8.5 and 200 times more likely to have a problem with their sight, and around 40% are reported to have a hearing impairment.¹⁹²
- Have dementia. For older adults with learning disabilities, the prevalence of dementia is 22%, compared with 6% in the general older adult population.
- Experience mental ill-health generally, with a prevalence of schizophrenia three times greater than other people (3% as against 1%).
- Contract gastrointestinal cancer (although people with a learning disability have a lower incidence of other types of cancer).¹⁹³

The leading cause of death for people with learning disabilities is respiratory disease – a rate of death of 46%-52%, compared with 15%-17% for the population as a whole. Coronary heart disease is the second most common cause of death, increasing as people get older. Around half of all people with Down's syndrome are affected by congenital heart problems.

Some of the key risk factors that affect people's health generally are also more of a problem for people with learning disabilities. They are more likely to be underweight, overweight or obese. Less than 10% of adults with learning disabilities eat a balanced diet: not knowing enough about healthy eating, not eating enough fruit and vegetables, and lacking choice. Over 80% of adults with learning disabilities engage in less physical activity than the minimum levels recommended by the Department of Health.¹⁹⁴

Recent information suggests that just under one in five (19%) people with learning disabilities smoke, a smaller proportion than in the population as a whole, where current rates are around 25%. The rate is higher among people with mild to moderate learning disabilities (30%) than people with severe learning disabilities (11%) and people with profound and multiple learning disabilities (4%). Rates of smoking are also higher among people living in private households.¹⁹⁵

Health services

Mainstream healthcare providers such as GPs, community pharmacists, dentists and acute hospitals can meet many, if not most, of the general health needs of people with learning disabilities. National policy emphasises the importance of making these services accessible. Key steps to achieve this include training staff in awareness and communication, liaison with specialist learning disability staff, and more effective strategies for involving people with learning disabilities.

There are also specialist services for people with more complex needs. These include:

- Acute inpatient assessment and treatment
- Specialist residential and day care
- Low, medium and high secure forensic services for people likely to become a danger to themselves or others
- Services for young people
- Short breaks
- Community learning disability teams
- Specialist teams that provide intensive support in people's homes.

In 2006/07, Government spending in England on the health aspects of caring for people with learning disabilities was estimated to be £2.5 billion.¹⁹⁶ It is unlikely that this captures

all funding for services used by people with learning disabilities.

National focus on learning disability

The publication in 2001 of the Government white paper *Valuing People* was a breakthrough in national policy. Cutting across health, education and social care, it set out a clear set of goals for improving the lives of people with learning disabilities. Key actions included ensuring that all people with learning disabilities were registered with a GP, improving support for people on health issues, providing individual health action plans, and an end to the NHS's historic role as a provider of residential accommodation.

While *Valuing People* has had an impact, insufficient progress has been made in the area relating to health.¹⁹⁷ During 2007/08, the Government carried out a consultation on *Valuing People Now*, to refresh its policy for people with learning disabilities. The consultation document included health as one of its top five priority areas for attention.¹⁹⁸

Over the last few years, a series of reports have highlighted serious deficiencies in the healthcare provided to people with learning disabilities. These include reports from the former Disability Rights Commission, Parliament, the independent inquiry chaired by Sir Jonathan Michael, our investigations and audits, and those of Healthcare Inspectorate Wales. The Michael report, *Healthcare for All*, appears to be having a major impact, with renewed Government focus on access to mainstream services. Over the next three pages, drawing on our findings and those of other bodies, we provide an overview of the current state of healthcare for people with learning disabilities.

Healthcare for people with learning disabilities

Q. Do mainstream services meet the physical health needs of people with learning disabilities?

A. This does not seem to be happening adequately. It is an issue that has been a consistent theme of recent national reports and inquiries.

Evidence suggests that adults with learning disabilities, when seeking access to mainstream services, are discriminated against because of their disability, and that there are barriers to registering with GPs.^{199,200} Too few organisations are aware of national guidance and best practice in providing care for people with learning disabilities. Services lack data and there are shortcomings in training for staff.²⁰¹

In Wales, access to care for short-term physical illness is generally good, but there is a lack of support in acute hospitals, which puts an extra burden on carers and families. There appears to be a better understanding of people's needs within primary care.²⁰²

Q. Are the health needs of people understood and planned for?

There are many needs of people with learning disabilities that are not being met, and evidence that they receive less effective care than they are entitled to.²⁰³ Both these factors suggest that the health needs of this group are not adequately understood.

Commissioning for people with a learning disability has already been identified as a major issue in Wales, and found to be poorly understood and managed at both national and local levels.²⁰⁴ We are looking at the state of commissioning in England, and will report on this in 2009. However, the evidence from our

recent audit of inpatient services suggests that there is limited engagement between commissioners and providers.²⁰⁵ Other recent reports have found little or no evidence of informed commissioning for this group.²⁰⁶

Q. Do people with learning disabilities get the right health checks?

People with a learning disability who have diabetes have fewer measurements of their body mass index than other people with diabetes. Those with stroke get fewer blood pressure checks. Rates of screening for both cervical and breast cancer are also lower than in the general population.²⁰⁷

Health checks for people with learning disabilities tend to uncover previously unmet health and healthcare needs.²⁰⁸ The Government has announced a system to reward GPs for providing annual health checks for people with learning disabilities.

Healthcare Inspectorate Wales (HIW) has found that, generally speaking, people on local authority registers for learning disability get annual health checks, although there are variations in the quality and consistency of these checks. However, this is only a limited picture, given that 47,000 of the estimated 60,000 people with a learning disability in Wales are not on these registers.²⁰⁹

Q. Are specialist health services safe?

We have carried out two major investigations into services provided for people with learning disabilities, where we found institutional abuse. This work prompted our comprehensive audit of inpatient learning disability services. In our audit, we found only a few services where the quality of care and the attention paid

to the safety of people with learning disabilities were uniformly good across all aspects of care.

We found that procedures for the safeguarding of vulnerable adults were poor, though we were reassured that procedures were robust in adolescent services. We could not be sure that the human rights of people with learning disabilities were always upheld, and we were concerned that access to advocacy services was patchy, given the value these services can have in providing outside scrutiny and highlighting poor practice.²¹⁰

Q. What is it like for people with learning disabilities who also have mental health needs?

In England, the national service framework for mental health applies to people with learning disabilities in the same way as everyone else. We have concerns that, as is the case with physical healthcare, people with learning disabilities and mental health needs are not included in mainstream services. We have, therefore, included in the 2008/09 annual

health check an indicator that looks at the mental health care provided by the NHS to people with learning disabilities.

In Wales, HIW has identified gaps in services for young people who need mental health care. They also found there to be no fully operational specific pathways of care for people with both learning disabilities and co-existing mental health problems. Training in mental health for learning disability nurses is reported to be insufficient. Professional boundaries within the NHS in Wales are leading to a fragmented service, as some medical professionals do not feel qualified to deal with both learning disabilities and mental health issues.²¹¹

Q. Are people listened to and fully involved in decisions about their care?

In England, we found that, on the whole, involving people in planning their own care is poorly done.²¹² In particular, few trusts had arrangements in place to listen to the views of young people, their families or the staff who care for them.²¹³



In Wales, HIW found a clear lack of investment in speech and language therapy, which is key to helping people communicate better – particularly in advocacy services, which help people protect against their vulnerability.

Q. Do people with learning disabilities get good access to wider activities, including social activities?

In England, we have found that some specialist inpatient services have good levels of stimulating activities and opportunities for people to take part but, in others, choice is limited.²¹⁴

Not all young people in specialist adolescent services are offered the range of fundamental experiences and support that they should have, such as socialising with friends or having opportunities for learning and employment outside their health setting. Outside agencies could be more involved in supporting young people and ensuring that they have access to such opportunities.²¹⁵

In Wales, the quality and depth of activity that is needed to help people to reach their maximum potential varies considerably. HIW has identified places of 'institutionalised comfort', where people are well cared for in terms of fundamentals, but lack stimulation.²¹⁶

985,000

Estimate of the number of people in England with a learning disability

What next?

- We have developed some new national indicators, including indicators on planning care, progress towards ending provision by the NHS of residential 'campus' accommodation, and the adoption of best practice in mental health services for people with a learning disability. These will be part of the 2008/09 annual health check.
- Our review of commissioning will be published during 2009.
- The establishment of the Care Quality Commission should provide new opportunities to look at the health and life outcomes experienced by people with learning disabilities, and the impact of public services on these.