



**Learning Disability
Professional Senate**

Learning Disability Professional Senate Briefing

**Required actions to address implementation failure for
people with a Learning Disability**

November 2025

Executive summary

- In the UK, an estimated 349,000 people aged under 18 years, and 1.2 million adults have learning disability.
- People with a learning disability can live rich and fulfilling lives and make a huge contribution to their communities. However, learning disability is associated with increased risk of mental health conditions, physical health conditions, preventable death, poverty, unemployment, poor housing, isolation, discrimination, bullying, abuse and victimisation. Parents and carers of people with a learning disability often provide lifelong care and support and are also at increased risk of mental health conditions. Such impacts have a human and financial cost.
- Effective interventions provided by various sectors exist to:
 - Address and prevent the mental and physical impacts of learning disability.
 - Address and prevent wider socioeconomic impacts including unemployment, poverty, isolation, stigma, discrimination and bullying.
 - Promote mental wellbeing and independence of people with a learning disability.
 - Promote physical health of people with a learning disability.
 - Support parents and carers of people with a learning disability.
 - Reduce the risk of some forms of learning disability through interventions before/during pregnancy.
- People with a learning disability have the same rights as everyone else. The rights of people with a learning disability are protected by statutory duties, legislation and policy to ensure that people with a learning disability receive the interventions they require. Furthermore, there is a legal duty to make reasonable adjustments so that mainstream services and support are accessible to all.
- However, only a minority of people with a learning disability receive intervention for associated mental health and physical health conditions with far less coverage of interventions to prevent these and wider impacts. Insufficient data exists on coverage and impacts of most interventions. The implementation gap breaches statutory legislation and results in population scale preventable suffering, broad impacts and inequalities for people with a learning disability. Changes as NHS England and the Department of Health and Social Care merge in the next two years as well as Integrated Care Board (ICB) budget cuts represent further risks to implementation.
- In England, a statutory duty exists for Integrated Care Partnerships to outline how assessed needs including for people with a learning disability are to be met by the Integrated Care Board, partner local authorities, and NHSE through the Integrated Care Strategy. In Northern Ireland, Scotland and Wales, similar but not equivalent statutory duties exist in country specific legislation.

Required actions to address the implementation gap for people with a Learning Disability

1. Transparent agreement on population coverage of different types of interventions for people with a learning disability provided by various sectors which takes account of statutory duties outlined above including to make reasonable adjustments to ensure access to mainstream services.
2. Delivery of a cross-government strategy and multi-agency shared outcomes framework to deliver 'fit for the future' for people with a learning disability. This would have designated ministerial responsibility and an associated implementation plan underpinned by required funding to meet the agreed coverage levels of interventions by different sectors.
3. Collection of data to monitor level of need and progress towards the agreed coverage and outcome levels of interventions.
4. National learning disability workforce strategy.
5. Development of comprehensive services across the life course for people with a learning disability.
6. Services for people with a learning disability to be co-produced so they are informed by lived experience.
7. Promote population awareness and understanding about the mental and physical health of people with a learning disability.

Learning Disability Professional Senate

The Learning Disability Professional Senate is made up of members of various professional Colleges and Societies which represent groups who provide specialist health support to children and adults with a learning disability. It covers the UK and aims to provide a single voice, which can lead and inform Department of Health and other strategic leads about the needs of people with a learning disability. The Senate provides cross-professional collaboration, strategic advice, and innovation to develop both mainstream and specialist services for people with a learning disability. The Senate recognises and works with the range of professionals to champion inter-agency, multi-disciplinary, holistic approaches for such services. The core Learning Disability Senate organisations include the British Association of Art Therapists, Association of Dance Movement Psychotherapy, British Association of Drama Therapists, British Association of Music Therapy, British Association of Social Workers, British Psychological Society, Chartered Society of Physiotherapy, National Ambulance Network, National Development Team for Inclusion, Royal College of General Practitioners, Royal College of Nursing, Royal College of Occupational Therapists, Royal Pharmaceutical Society, Royal College of Psychiatrists, Royal College of Speech and Language Therapy, and Skills for Care. Regular input is also received from the Challenging Behaviour Foundation, Department of Health and Social Care, Departments of Health from Wales, Scotland, and Northern Ireland, Learning Disability England and NHS England.

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Appendix 1. Legislation and policy for learning disability

Appendix 2. Legislation and policy for learning disability in Northern Ireland

Key messages

- People with a learning disability can live rich and fulfilling lives and make a huge contribution to their communities.
- People with a learning disability have the same rights as everyone else. The rights of people with a learning disability are protected by statutory duties, legislation and policy to ensure that they receive the interventions they require. Furthermore, there is a legal duty to make reasonable adjustments so that mainstream services and support are accessible to all including people with learning disability.
- People with a learning disability are at increased risk of mental, physical and wider impacts. Effective interventions exist to treat and prevent learning disability associated mental health and physical impacts. Effective interventions also exist to address and prevent wider impacts as well as reduce the risk of some forms of learning disability.
- However, only a minority of people with a learning disability receive intervention for associated mental health and physical health conditions with far less coverage of interventions to prevent these and wider impacts. The implementation gap breaches statutory legislation and results in population scale preventable suffering, broad impacts and inequalities for people with learning disability. Changes as NHS England and the Department of Health and Social Care merge in next two years as well as ICB budget cuts represent further risks to implementation.
- Statutory duties exist to assess size unmet need for such interventions for people with a learning disability and how such needs are to be addressed.
- This briefing makes seven recommendations to sustainably address the implementation gap for people with a learning disability which will result in broad benefits for people with learning disability, their families and society.

Introduction

In the UK, an estimated 349,000 people aged under 18 years and 1.2 million adults have a learning disability.

People with a learning disability can live rich and fulfilling lives and make a huge contribution to their communities. This briefing describes the impacts and inequalities experienced by people with a learning disability which result in significant human and financial costs. It sets out interventions to both address and prevent such impacts as well as promote mental wellbeing. The rights of people with a learning disability are protected by statutory duties, legislation and policy to ensure that people with a learning disability receive the interventions they require. Furthermore, there is a legal duty to make reasonable adjustments so that mainstream services and support are accessible to all.

However, a large proportion of people with a learning disability do not have access to such interventions which breaches the Equality Act and their right to health. The implementation gap results in population scale preventable suffering, broad impacts and associated economic costs. In England, Integrated Care Partnerships have a statutory duty under the Health and Social Care Act (DHSC, 2022) to outline how assessed needs including for people with a learning disability are to be met by the Integrated Care Board, partner local authorities, and NHSE through the Integrated Care Strategy. In Northern Ireland, Scotland and Wales, similar but not equivalent statutory duties exist in country specific legislation since health and social care is a devolved responsibility. Furthermore, the Act includes specific duties that all staff working in health and care settings have training on learning disability and autism appropriate to their role.

The briefing makes seven recommendations to address this implementation gap and thereby meet statutory duties and enhance the quality of life and wellbeing of people with a learning disability.

1. Defining learning disability

- Learning disability can be defined as a significantly reduced ability to understand new or complex information, to learn new skills (impaired cognition, with a reduced ability to cope independently (impaired social functioning) which starts early in life typically before school age. The term intellectual disability is increasingly being used internationally in order to adopt more inclusive language and reduce stigma.
- Learning disability can be classified as mild, moderate, severe or profound. In all cases, learning disability is a lifelong condition and cannot be “cured” although most people with a learning disability can continue to acquire skills and competencies throughout their life particularly if provided with optimal care, education, learning opportunities and training.
- Several conditions including neurological conditions, Down syndrome, autism, meningitis, epilepsy or cerebral palsy are associated with or cause some types of learning disability.
- Learning difficulty and learning disability: Learning disability is distinct from learning difficulty, which is a reduced intellectual ability for a specific form of learning and includes specific conditions such as dyslexia (reading), dyscalculia (numbers) and dyspraxia (affecting physical co-ordination). A person with a learning disability may also have one or more learning difficulties.
- Borderline Intellectual Functioning (BIF) refers to people with an intelligence quotient (IQ) between 70 and 85, which place them between typical intellectual functioning and learning disability. People with BIF often face difficulties with adaptive skills, and have higher risks for mental health conditions, poor health outcomes and social challenges (Lim et al, 2022). They are a significant user of primary and secondary healthcare, have higher rates of self-harm and suicide attempts, treatment with psychiatric medication or therapy, and psychiatric admission.
- This briefing considers people who have a learning disability. This group will include some people who are also autistic who experience a comparable but different set of inequalities. People from other groups which experience inequalities and also have a learning disability experience even greater levels of inequalities (White et al, 2023).

2. Prevalence of learning disability in the UK

- Child learning disability: 2.5% (349,000 people aged under 18) (PHE, 2016; ONS, 2024; Mencap).
- Adult learning disability: 2.2% (1.2 million people) (PHE, 2016; ONS, 2024; Mencap).
- Borderline intellectual functioning: 12.8% (Lim et al, 2022).

3. Impacts of having a learning disability

This section on impacts of having a learning disability highlights the greater needs of people with a learning disability compared to the general population. This section summarises the following types of impact.

- 3.1 Mental health impacts
- 3.2 Physical health impacts
- 3.3 Wider impacts
- 3.4 Parents, family and carer impacts

3.1 Mental health impacts

- Increased risk of any mental health condition
 - Proportion of mental health conditions was 36% among British children with a learning disability compared to 8% without a learning disability (Emerson & Hatton, 2007). British children with a learning disability comprise 14% of all British children with a mental health condition.
 - Rate of mental disorder was 3-4 higher in children with intellectual disability and intellectual developmental disorders (Munir, 2016).
 - Rate of mental health problems was significantly higher in British adults with intellectual disability compared to those without intellectual disability (Hatton et al, 2017).
 - Rate of mental health conditions was higher among Scottish people with learning disabilities (Hughes-McCormack et al, 2017). Proportion with a mental health condition was 23% for adults with a learning disability compared to 5% without and 27% for older adults with a learning disability compared to 4.5% without.
 - Clinical presentation of mental health conditions in people with a learning disability differs from the general population particularly in those with significant cognitive and communication impairments.
- Increased risk of particular mental health conditions
 - Severe mental illness (SMI): People with learning disabilities were eight times more likely than the general population to be recorded as having SMI after adjusting for age and sex profile (NHSD, 2019).
 - Dementia: Risk for people with a learning disability was five higher than the general population (Strydom et al, 2013; NHSD, 2016).
 - Autism: Rate among people with a learning disability in England was 33.3% compared to 1.2% of people without a learning disability (NHSD, 2024).
 - ADHD: Rate among people with a learning disability in England was 9.0% compared to 1.2% of people without a learning disability (NHSD, 2024).
- Challenging behaviour (NICE, 2015; NICE, 2018): Approximately 15-20% in people with a learning disability known to services have a challenging behaviour (Bowring et al, 2019). Higher rates occur with more severe learning disability (Bowring et al, 2019) and with a learning disability associated with autistic spectrum disorder and attention deficit hyperactivity disorder. A significant proportion of challenging behaviours are associated with mental or physical health issues.
- Suicide: Mental health conditions in people with a learning disability are associated with increased risk of suicide (Chan & Bhandarkar, 2025).

3.2 Physical health impacts

- Insufficient physical activity (Emerson et al, 2010 ; Dairo et al, 2016).
- Increased risk of obesity (NHSD, 2023): UK children with a learning disability were significantly more likely than other children to be obese at ages five, seven and eleven (Emerson et al, 2016). Among children with a learning disability, risk of obesity at age eleven was associated with persistent maternal obesity, maternal education, child ethnicity and

being bullied at age five. Prevalence of obesity is much higher into adulthood: For 25-34-year-olds, 29% of people with a learning disability experience obesity compared to 6% without a learning disability. Poor nutritional knowledge within the learning disability population and their family carer networks is an additional barrier to healthy weight. Furthermore, contention exists regarding capacity and food choice, causing confusion with how to support somebody to make healthy changes (Morris & Julian, 2024).

- Smoking: This is the single largest cause of preventable death in the UK where rates are similar in adolescents with and without a learning disability (Emerson, 2023). Smoking rates among people with a learning disability have reduced more slowly than among people without a learning disability (Emerson, 2023). Increased risk of cardiovascular disease, diabetes, particular types of cancer, gastrointestinal conditions (Curtis et al, 2021), sensory impairment and epilepsy (Robertson et al, 2015).
- Physical health conditions: People with a learning disability are at higher risk of physical health conditions (Cooper et al, 2018; Liao et al, 2021) including diabetes (Baksh et al, 2023) and hypothyroidism. Coeliac disease affects 5-6% and autoimmune thyroid disease 13-34% of those with Down syndrome (Du et al, 2017; Hom et al, 2024). Physical health impacts are amplified by the individual's inability to report and manage these needs as well as increased rates of prescribing of antipsychotic medication in the absence of mental health conditions (see section 5.1.2).
- Comorbidity: People with a learning disability are more likely to have other health conditions compared to those without (Cooper et al, 2015). Proportion of people with a learning disability with three conditions was 11% compared to 7% without learning disability. Although comorbidity increases with age, it is highly prevalent at all ages.
- Premature death: Median age at death for people with a learning disability:
 - England: 62 years compared to 82.7 years for the general population (White et al, 2023). Proportion of deaths from an avoidable cause which could have been prevented by good quality healthcare was 49% for people with a learning disability compared to 22% for the general population.
 - Scotland: 65 years compared to 80 years for the general population (Rydzewska et al, 2025). For people with a learning disability, 32% of recorded deaths were considered avoidable, 21% were treatable and 20% were preventable compared to people without a learning disability where 18% of deaths were considered avoidable, 9% treatable and 15% preventable.
 - Preventable deaths were higher for persons with a mild learning disability compared to a severe learning disability while treatable and unavoidable mortality were highest for persons with a severe learning disability (Thygesen et al, 2024).

3.3 Wider impacts

A wider range of impacts which for some are cumulative include:

- Poverty and poor housing (Emerson & Baines, 2010; Emerson, 2012).
- Social: Isolation and loneliness (Emerson et al, 2021), reduced social participation (Taheri et al, 2016).
- Unemployment: 71% gap in employment rate between people who in receipt of long-term support for a learning disability (aged 18-64) and overall employment rate (2022/23) (England).
- Discrimination (Emerson & Baines, 2010).
- Bullying, abuse including sexual abuse (Byrne, 2018) and being victims of crime (Emerson et al, 2009; Emerson et al, 2012; Chatzitheochari et al, 2016).

3.4 Parents, family and carer impacts

Since a learning disability is a lifelong condition, often family carers provide lifelong support (in contrast with other caring roles which can be shorter term or time limited).

- Parents, family and carers of people with a learning disability are at increased of mental health conditions.
- Mothers of people with a learning disability have significantly poorer mental health than typically developing people (Rydzewska et al, 2021).
- Mothers of children with a learning disability significantly more likely to have poor general mental health and well-being as well as higher levels of depression, stress and anxiety compared with fathers of children with a learning disability (Dunn et al, 2019).
- Lack of appropriate respite or short breaks can have significant impact.

4. Effective Interventions for people with a learning disability

Interventions can be categorised as different levels of prevention (primary, secondary and tertiary), promotion and support (Campion, 2019; Campion et al, 2022).

- 4.1 Primary prevention
- 4.2 Secondary prevention
- 4.3 Tertiary prevention
- 4.4 Promotion of mental wellbeing
- 4.5 Promotion of physical health
- 4.6 Parent, family and carer support

4.1 Primary Prevention

- Prevention of impacts of learning disability outlined in section 3 which contribute to people with a learning disability living healthy lives and promoting the best health a person can have:
 - Mental health impact prevention: For instance, poverty alleviation since 20-50% of increased risk of mental health condition in children with a learning disability was accounted for by low socioeconomic status (Emerson & Hatton, 2007). Poverty also contributes to other impacts including healthy nutritional choice.
 - Physical health impact and premature mortality prevention: Lifestyle changes are important to address obesity, physical inactivity, poor nutrition (Heslop & Lauer, 2024) and smoking (Emerson, 2023). For instance, a recent large Danish study estimated that for people with learning disability, 58% of premature deaths were preventable including through reducing smoking and alcohol intake or by vaccination, as well as by earlier diagnosis and treatment (Thygesen et al, 2024). Most of the literature regarding preventative strategies for the general population such as vaccination is applicable to people with a learning disability although some reasonable adjustment would be required.
 - Obesity prevention includes national efforts to improve education for people with a learning disability and provide online training (NHSE, 2025). Improving diet is best achieved by making environmental level changes rather than focusing on the individual (Dean et al, 2021). Further enablers for weight loss include accessible information, motivated, positive and consistent staffing, as well as presenting healthy food in a positive way and forward planning to resolve environmental triggers (Spanos et al, 2013; Doherty et al, 2018; Doherty et al, 2020; Skelly et al, 2021).
 - Socioeconomic impact prevention: Interventions to address unemployment, poverty and poor housing.
 - Isolation and loneliness prevention (Emerson et al, 2021).
- Prevention of discrimination (Emerson & Baines, 2010), bullying, abuse and victims of crime.
- Reducing the risk of developing some forms of learning disability including during pregnancy and birth (NICE, 2025).

4.2 Secondary prevention

Early intervention to address and prevent associated:

- Health impacts such as mental health conditions and associated suicide risk, obesity (Morris & Julian, 2024) and physical health conditions including through regular screening.
- Wider impacts outlined in section 3 including unemployment and social isolation.

4.3 Tertiary prevention

- Treatment pathways should be available to people with a learning disability as they are for people without a learning disability.
- Interventions to effectively manage mental health conditions and challenging behaviours (NICE, 2015; NICE, 2018; Groves et al, 2023). Such interventions can be provided by a range of providers including dedicated community learning disability services which are able to offer adapted assessment and intervention approaches.
- Management of physical health conditions such as epilepsy and obesity.

4.4 Promotion of mental wellbeing

Promotion of protective factors for mental wellbeing including social interaction and support, physical activity, meaningful engagement in activities and employment as well as a sense of agency and control (Campion, 2019; Campion et al, 2022).

Promotion of mental wellbeing also contributes to prevention of associated impacts of learning disability outlined in section 3.

4.5 Promotion of physical health

Interventions to improve physical health include a healthier diet and physical activity leading to reduced risk of obesity.

4.6 Parent, family and carer support

Family carers provide lifelong care, advocacy and support for their learning-disabled relatives although are at increased risk of associated challenges. However, families and carers often receive little support themselves which impacts on their own physical and mental health which in turn impacts on the physical and mental health of the person with learning disability. Appropriate support for parents, families and carers is a key component of effective support for people with learning disability.

5. Implementation gap for people with a learning disability in the UK

Implementation gap for:
5.1 Mental health care for people with a learning disability
5.2 Physical health care for people with a learning disability
5.3 Social health for people with a learning disability
5.4 Carer support for people with a learning disability
5.5 Prevention of risks for developing a learning disability

The implementation gap is the difference in the number who would benefit from an intervention compared to the number who actually receive the intervention.

The UK has an education health and social care system which is meant to provide greater levels of support to people and families who are more in need. This includes support and services for children and adults with learning disabilities, who should, with the necessary reasonable adjustments required by law be able to access mainstream services, and when required, specialist support and services.

Section 2 highlighted that 2.5% of children and 2.2% of adults have a learning disability (PHE, 2016; ONS, 2024; Mencap). This section highlights the implementation gap resulting in further inequalities and includes mental health care (5.1), physical health care (5.2), social health care (5.3), carer support (5.4) and reducing risk for developing a learning disability (5.5). Following information about coverage was obtained for England but was not available for Northern Ireland, Scotland and Wales.

5.1 Mental health care for people with a learning disability

Data below refers to people on the learning disability register in primary care in England. However, less than 25% of people with a learning disability in England are on the learning disability register (section 5.2).

5.1.1 Diagnosis of mental health conditions in people with a learning disability

England (NHSD, 2024)

- Learning disability and autism diagnosis: Proportion on learning disability register with autism diagnosis increased from 21.4% in 2017/18 to 33.3% in 2023/24.
- Learning disability and ADHD diagnosis: Proportion of people with a learning disability and ADHD diagnosis increased from 5.5% in 2017/18 to 9.0% in 2023/24.
- Learning disability and anxiety: Proportion of people with a learning disability and anxiety diagnosis was 9.9% in 2023/24.

5.1.2 Prescribing of antidepressants and antipsychotics in people with a learning disability

England (2023/24) (NHSD, 2024)

- Antidepressants: Proportion of people on the learning disability register prescribed antidepressants was 22.1% compared to 10.9% without learning disability.
- Antipsychotics: People with a learning disability without another mental health condition are prescribed much higher rates of antipsychotic medication. Good prescribing and deprescribing practice is required to minimise harm linked to inappropriate or over prescribing as set out by NHSE's stopping over medication of people with a learning disability and autism (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP) (NHSE, 2019; Swanepoel & Lovell, 2023).
 - Proportion with a learning disability prescribed antipsychotics who do not have a diagnosis of SMI or are not on the palliative care register was 8.4% compared to 0.4% without a learning disability (2023/24) (NHSD, 2024).
 - Proportion with a learning disability prescribed antipsychotics reduced from 15.5% in 2017/18 to 13.9% in 2023/24 compared to 0.9% without a learning disability although this data only represented 57% of primary care.
 - Proportion with a learning disability without mental illness who were prescribed antipsychotics fell from 9.4% in 2017/18 to 8.4% in 2023/24.

5.1.3 Secondary care for people with a learning disability

Number of learning disability beds in England reduced by

- 10.1% between 2001-2010, a further 8.9% between 2010 and 2019, and a further 11.2% between 2019 and 2023 (DHSC, 2024; NHSD, 2024)
- 98.7% between 1960 and 2020 (Keown et al, 2025)

5.1.4 Prevention of mental health conditions

- Lack of information including on poverty alleviation.

5.2 Physical health care for people with a learning disability

- Primary care for people with a learning disability
 - 2.5% of children and 2.16% of adults have a learning disability (PHE, 2016; ONS, 2020; Mencap).
 - Proportion of adults reporting to primary care that they had learning disability: 1.9% (England) (2022/23).
 - Proportion of adults on learning disability register: 0.5% (2023/24) (England) (NHSD, 2024). This suggests that less than 25% of people with a learning disability in England were on the learning disability register.
 - Annual health checks
 - NICE recommends that people of all ages with a learning disability should be offered a health check. However, the UK government has recently removed the target of annual physical health checks for people with a learning disability although ICBs will be expected to ensure that annual health checks continue at the local level.
 - Proportion on learning disability register having an annual physical health check from primary care increased from 59.3% in 2018/19 to 79.6% in 2023/24 (NHSD, 2024).
 - Proportions were higher for white people (73.4%) compared to Asian or Asian British (67.4%) or Black, African, Caribbean or Black British (68.4%) (2023/24) (England) (NHSD, 2024).
 - While less than 25% of people with a learning disability are on the learning disability register (see above), no information was available about interventions implemented as a result of the physical health check or associated outcomes.
- People from ethnic minority groups experience even greater inequalities in health care (Umpleby et al, 2023).
- Prevention of physical health issues in people with a learning disability
 - Flu vaccination: Proportion with a learning disability having flu vaccination was 54.3%. However, proportions were higher for white people (59.1%) compared to Asian or Asian British (43.6%) or Black, African, Caribbean or Black British (34.7%) (2023/24) (England) (NHSD, 2024).
 - Smoking cessation: Lack of information.
- Cancer screening
 - Proportion of women aged 50-69 with a learning disability in England receiving breast cancer screening was 14.2% lower than for people without a learning disability between 2017 and 2022 (NHSD, 2022).

- Proportion of people with a learning disability in England receiving colorectal cancer screening between 2020 and 2022 was 18% lower than for people without a learning disability (NHSD, 2022).
- Physical activity promotion: Lack of information.
- Nutrition intervention: Lack of information.

5.3 Social health for people with a learning disability

- Employment: 70.9% gap in employment rate between people who in receipt of long-term support for a learning disability (aged 18-64) and overall employment rate (2022/23) (England).
- Accommodation: Proportion of adults with a learning disability living in stable and settled accommodation: 80.5% (2022/23) (England).
- Direct payments: Proportion of adults with a learning disability receiving direct payments: 30.3% (2019/20) (England).

5.4 Carer support for people with a learning disability

- Carers have expressed concerns about their unmet support needs and access to learning disability support services (James, 2013; Wodehouse & McGill, 2009).
- Lack of available data on coverage of interventions for carers.

5.5 Reducing risks for developing a learning disability

- People requiring more targeted support and monitoring to them and their baby to give them the best chance of health including during pregnancy and birth (NICE, 2025).
- Proportion receiving intervention to address prenatal factors: No information obtained for maternal alcohol use, tobacco use, diabetes, hypertension, epilepsy or asthma.
- Proportion receiving intervention to address perinatal factors: No information obtained for interventions to prevent preterm birth or low birth weight.

6. Causes of the learning disability implementation gap

- 6.1 Insufficient information about size of implementation gap
- 6.2 Lack of coverage targets for many interventions
- 6.3 Insufficient staff and resource allocation
- 6.4 Insufficient staff training
- 6.5 Failure to make reasonable adjustments by broad range of services and providers
- 6.6 Specific reasons for lack of access to quality healthcare
- 6.7 Primary care factors

Causes of the implementation gap are important to understand to address the gap. This is an important part of any national policy. These include:

- 6.1 Insufficient information about estimated size of need or coverage/outcomes of public mental health interventions.
- 6.2 Lack of coverage targets for many interventions.
- 6.3 Insufficient staff and resource allocation.
 - Insufficient staff:
 - Reduction in NHS learning disability nursing staff (FTE) between 2010/11 and 2023/24 in England (DHSC, 2024; NHSE, 2024): London (-13.3%), South West (-29.2%), North West (-40.8%), Midlands (-43.5%), North East & Yorkshire (-47.8%), South East (-52.4%), East of England (-55.3%).
 - Insufficient registered nurses in learning disability is leading to substitutions with other fields of nursing.
 - No medical specialists for people with a learning disability.
 - Lack of information about national resource allocation
- 6.4 Insufficient staff training: Staff having little understanding about learning disabilities. This links to the impact of eligibility criteria so that counselling for a person with a learning disability is withheld because staff cannot adapt their practice for people with a learning disability. Furthermore, the complexity that can be required in adapting an intervention for

people with a learning disability needs to take account of each individual's engagement and communication styles and may require interventions that are not provided outside learning disability services.

6.5 Failure to make reasonable adjustments by broad range of services and providers.

6.6 Specific reasons for lack of access to quality healthcare (Heslop et al. 2013; Tuffrey-Wijnes et al. 2014):

- Insufficient identification of people with a learning disability including in primary care (Wigham et al, 2023)
- Failure to recognise that a person with a learning disability is unwell and to make a correct diagnosis. Diagnostic overshadowing further attributes symptoms to the learning disability. Many people with a learning disability are unable to sufficiently communicate their needs or feelings.
- Anxiety or a lack of confidence for people with a learning disability.
- Challenging behaviours of some people with a learning disability.
- Failure for healthcare providers to make reasonable adjustments.
- Lack of joint working from different care providers.
- Insufficient involvement from carers including family and paid carers.
- Inadequate aftercare or follow-up care.
- Stigma and discrimination including by health professionals (Pelleboer-Gunnink et al, 2017).
- Lack of *accessible* transport links.

6.7 Primary care factors

- GPs experience problems in fulfilling their roles in caring for patients with both learning disability and mental health conditions, and gaps are identified regarding effective GP training programmes, applicable guidelines and tools, optimal collaborative mental health care, and corresponding payment models (Pouls et al, 2022). Improvement required in the current quality of GP care to patients with learning disability and mental health conditions can be achieved by bridging the identified gaps and initiating close collaborations between care professionals, policymakers and organisational managers.
- Reasonable adjustments and facilitators can be implemented to ensure that people with a learning disability are not excluded from primary health care (Doherty et al, 2020).

7. Rights of people with learning disability and associated statutory duties

Children and adults with learning disabilities have the same Human Rights as everyone else. Appendix 1 highlights a broad range of legislation and policy to ensure that people with a learning disability receive the interventions they require. There is a legal duty to make reasonable adjustments so that mainstream services and support are accessible to all. Together, the legal and the education, health and social care systems should ensure that children and adults with learning disabilities exercise their legal and human rights to experience the same life opportunities as everyone else. However, while reasonable adjustments will address challenges for some, those with more complex needs may require more specialist learning disability services.

Furthermore, in England Integrated Care Partnerships have a statutory to outline how assessed needs including for people with a learning disability are to be met by the Integrated Care Board, partner local authorities, and NHSE through the Integrated Care Strategy under the Health and Social Care Act (DHSC, 2022). In Northern Ireland, Scotland and Wales, similar but not equivalent statutory duties exist in country specific legislation since health and social care is a devolved responsibility.

All organisations that provide NHS care and publicly funded adult social care are also legally required to follow the NHS Accessible Information Standard which sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

8. Required actions to address the implementation gap for people with a learning disability

People with a learning disability are at increased risk of mental, physical and social adverse impacts. Effective interventions exist to treat and prevent learning disability associated mental health and physical impacts. Effective interventions also exist to address social impacts and reduce the risk of some forms of learning disability from arising. However, only a minority of people with a learning disability receive treatment for associated mental health and physical health conditions with far less coverage of interventions to prevent such impacts. Insufficient data exists on coverage and impacts of most interventions. The implementation gap breaches statutory legislation and results in population scale preventable suffering, broad impacts and associated economic costs. Furthermore, massive changes as NHSE and DHSC merge in the next two years as well as large cuts to ICB budgets represent significant additional risks to implementation, locally based work and national priorities.

Required actions to address the implementation gap

- 8.1 Transparent agreement on population coverage of different types of intervention for people with a learning disability
- 8.2 Delivery of a cross-government learning disability strategy and multi-agency shared outcomes framework
- 8.3 Collection of data to monitor level of need and progress towards agreed coverage and outcome levels of interventions
- 8.4 National learning disability workforce strategy
- 8.5 Development of comprehensive pathway for people with a learning disability
- 8.6 Services for people with a learning disability to be co-produced with people with lived experience
- 8.7 Promotion of population understanding about the mental health of people with a learning disability

8.1 Transparent agreement on population coverage of different types of intervention for people with a learning disability

Government and multi-agency stakeholders to transparently agree on the acceptable level of population coverage of different types of intervention for people with a learning disability by various sectors. Stakeholders should include people with a learning disability, parents/carers, primary care, learning disability services, secondary care, secondary mental health care, social care, health and social care leaders, antenatal care, schools, public health, voluntary sectors, policy makers and government including treasury. When agreeing level of coverage, stakeholders must consider:

- Impact and economic cost of implementation failure.
- Broad impacts and associated economic benefits of improved coverage.
- Rights of people with a learning disability, statutory duty to protect people with a learning disability and the statutory duty of services to make reasonable adjustments.
- UN Sustainable Development Goal (SDG) target of universal health coverage.

8.2 Delivery of a cross-government learning disability strategy

Government across the four nations of the UK to prioritise the mental and physical health of people with a learning disability through delivery of a cross-government strategy and a national, multi-agency shared outcomes framework in order to provide 'fit for the future' for people with learning disability. This would have designated ministerial responsibility and an implementation plan underpinned by the required resource and staffing to meet the agreed coverage levels of interventions by different sectors.

8.3 Collection of data to monitor level of need as well as progress towards agreed coverage and outcomes of interventions

Expansion of routine, regular government-funded data collection is required for the health of people with a learning disability as well level of provision and outcomes of different types of intervention together with a nationally agreed outcomes framework. This will inform regular assessment of the implementation gap for people with a learning disability in order to monitor progress towards agreed coverage levels and associated outcomes.

8.4 National learning disability workforce strategy

The Health and Social Care Act (DHSC, 2022) includes specific duties that all staff working in health and care settings should have training on learning disability and autism appropriate to their role. Training supports identification of people

with a learning disability and mental health conditions in primary and social care (Wigham et al, 2024). It also includes that providers of NHS and publicly funded social care should deliver training to staff in the use of the 'Reasonable Adjustment Digital Flag' (Morris & Julian, 2024). This should ensure that staff understand how to record and share details of reasonable adjustments that people with a disability or impairment require to access services. Training should be used to improve awareness of the range of adjustments that can be provided, such as longer appointment times, and the flag should be rolled out across all services. The Oliver McGowan Mandatory Training on Learning Disability and Autism was updated in February 2025 (NHSE, 2025).

A national learning disability specific workforce strategy would build on the National Competencies Framework (Skills for Health, Health Education England & NHS England, 2019). The workforce strategy would need to include plans for recruitment and retention of specialist roles to address the significant gaps in the health and social care workforce for people with learning disability. The Royal College of Nursing is undertaking a learning disability nursing review which aims to promote the importance of learning disability nursing and potential future developments given the well cited crisis in learning disability nursing.

8.5 Development of comprehensive pathway for people with a learning disability

A comprehensive pathway would support the identification of children with a learning disability within primary and secondary care. It would also support discussion with parents and patients towards preparation for adulthood where it may then be more obvious that a learning disability is present due to developmental issues. This would also help with making reasonable adjustments for people to ensure effective health and care access in their lives.

8.6 Services for people with a learning disability to be co-produced with people with lived experience

This needs to ensure the lived experience provides representation for people who need support.

8.7 Promotion of population understanding about the mental health of people with a learning disability

This would include raising awareness including among people with a learning disability (Wigham et al, 2023) as well as actions to address associated stigma.

9. Conclusion

People with a learning disability can live rich and fulfilling lives and make a huge contribution to their communities. However, having a learning disability is associated with a broad range of impacts. Despite the existence of effective interventions, only a minority of people with a learning disability receive interventions for associated mental health and physical health conditions with far less coverage of interventions to prevent these and wider impacts. The implementation gap breaches statutory legislation and results in population scale preventable suffering, broad impacts and inequalities for people with a learning disability. The recommendations of this briefing support the required actions to address implementation failure and will result in broad benefits for people with learning disability, their families and society.

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Appendix 1. Legislation and Policy for Learning Disability

- Mental Health Act (1983) states that a person may not be considered to be suffering from a mental disorder simply as a result of having a learning disability, unless that disability is associated with abnormally aggressive or seriously irresponsible conduct.
- Human Rights Act (1998) places a clear legal duty on public officials and bodies to 'respect' the 16 rights it outlines and to take action to ensure people's rights are 'protected'.
- Valuing People (2001): White Paper which included government pledges to ensure that people with a learning disability had the same right of access to health services as everyone else.
- Mental Capacity Act (2005) supports people who may lack capacity to make decisions on their own get the support they need to make those decisions. Where they are not able to make their own decision, the Mental Capacity Act says a decision must be made that is in their 'best interests'.
- Valuing People Now (2009): Government three-year strategy that reiterated the objectives of 2001 Valuing People White Paper to improve outcomes for people with a learning disability.
- Equality Act (2010) places a statutory duty on employers, healthcare settings and wider society to make reasonable adjustments to ensure equity of access to services for people with a disability, by making changes in their approach or provision.
- Confidential Inquiry into Premature Deaths of People with Learning Disabilities (2013) Investigated the avoidable or premature deaths of people with a learning disability across the South West of England and made recommendations to prevent future deaths.
- Care Act (2014) Strengthened the rights of people with a learning disability and their carers to assessment and support for care needs, as well as setting national thresholds for eligibility.
- Building the Right Support (2015) National plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display challenging behaviour, including people with a mental health condition.
- Accessible Information Standard (2016) This aims to make sure that health and care services give people with a learning disability or sensory loss information in a way they can understand. All organisations that provide NHS care or publicly funded social care are legally required to follow the standard.
- Health Charter for Social Care Providers (2017) Aimed at social care providers and staff and provides guidance to help people with a learning disability get better access to medical services to improve their health.
- NHS Long Term Plan (2019) Sets out NHS commitments for improving the health of people with a learning disability.
- Core20PLUS5 (2021) NHSE's approach to reducing health care inequalities. People with a learning disability and autistic people are one of the 'PLUS' groups that should be considered when looking at health inequalities.
- Building the Right Support for People with a Learning Disability and Autistic People (2022) Plan from the Department of Health and Social Care focusing on six areas to develop community services and reduce reliance on mental health inpatient care.
- Health and Care Act (2022) This introduced a requirement that all regulated health and social care service providers ensure their staff receive learning disability and autism training that is appropriate to their role.
- Down Syndrome Act (in preparation): Statutory guidance that is being produced under the Act, which will be out for public consultation in 2025. Information will be included throughout on commissioners' existing duties under the Equality Act 2010 and how the guidance could be used to help meet the needs of people with similar needs in accordance with duties in that Act.
- LGA. Council social care support for people with lifelong disabilities. Local Government Association; 2023. <https://www.local.gov.uk/publications/council-social-care-support-people-lifelong-disabilities>
- LDE. Good Lives Manifesto. Learning Disability England; 2024. <https://www.learningdisabilityengland.org.uk/good-lives-manifesto-2024/>

Appendix 2. Legislation and policy for learning disability in Northern Ireland

- Chronically Sick and Disabled Person Act (1978).
- Mental Health (Northern Ireland) Order (1986).
- Disabled Persons (NI) Act (1989).
- The Children's (Northern Ireland) Order (1995): This is the main legislation relating to children in Northern Ireland. An important feature of the legislation is that it generally directs judges to have regard to the child's welfare in view of all the circumstances. The child's welfare is the paramount consideration and so is more important than any other factor. It means making a decision that is best for the child. It is known as the Welfare or Paramountcy Principle.
- Disability Discrimination Act (1995): This makes it unlawful to discriminate against people based on disability in various areas, including employment and the provision of goods and services. While it has been repealed and replaced by the Equality Act 2010 in other parts of the UK, it remains in effect in Northern Ireland.
- Carers and Direct Payments Act (Northern Ireland) (2002): Self-Directed Support is a term used to describe the ways in which social care services and support can be offered to people and families. It gives greater control to the person who needs social care and to those close to them, to ensure they can shape the support they need to suit their lives
- Health and Social Care (Reform) Act (Northern Ireland) (2009): the provision of social care including for people with a learning disability is provided under Health and Personal Social Services (Northern Ireland) Order (1972) Health and Social Care (Reform) Act (Northern Ireland) (2009).
- Autism Act (Northern Ireland) (2011): This legislation mandates the development of an autism strategy and amends the Disability Discrimination Act 1995 to better address the needs of people with autism spectrum disorders.
- Mental Capacity Act (NI) (2016): This legislation is not fully implemented but when it is it will combine mental capacity and mental health legislation for those 16 and over, as recommended by the Bamford Review. The Act offers guidelines for those unable to decide and supports future planning, and focuses on supporting people to make their own decisions.
- Strategic Frameworks
 - Equal Lives (Bamford Review): The Department of Health in Northern Ireland started an independent review in 2002. This review looked into laws, policies and services for people with a learning disability and/or mental health needs. The report that came out of this was called The Bamford Review. Equal Lives Report, published in 2005, followed which set out a vision for creating services for men, women and children with a learning disability for the next 15 to 20 years. This is currently under review.
 - Autism Strategy: The Department of Health published this cross-departmental strategy in December 2023, which runs until 2028. It sets out the key commitments and actions needed to enhance and improve support for autistic people and their families. A further delivery plan is due to be developed in 2025.