

Suffolk County Council

Learning disabilities needs assessment 2021

Evidence review: Best practice and interventions supporting people with learning disabilities

Literature review undertaken by Helen Benson, Public Health Speciality Registrar
Lead Consultant: Dr Mashbileg Maidrag, Consultant in Public Health
November 2021



Contents

Introduction	2
The NHS Long Term Plan 2019.....	2
Care and Support Statutory Guidance	2
Informed choices and personalisation of care provision.....	3
Housing needs and recommendations for support	3
Day services, activities and community provision for adults with LD.....	3
Access to leisure services and activities.....	3
Personal budgets and direct payments	4
Employment support	4
Safeguarding	4
Provision for children and young people with learning disabilities.....	4
Transition to adult services.....	5
Staff training.....	5
Guidance and recommendations for best practice for supporting people with learning disabilities during the COVID-19 pandemic.....	6
Best practice for Health Services in meeting the needs of people with learning disabilities.....	6
Interventions and recommendations for best practice to reduce specific health inequalities.....	6
Annual health checks	6
Cancer screening	6
Flu vaccination uptake	6
Mental health outcomes.....	7
Dementia.....	7
Dental health outcomes.....	7
Weight management and increasing physical activity levels	7
Diabetes care and prevention of diabetes.....	7
Access to relationship education and sexual health services.....	7
End of life care and bereavement support	7
Glossary.....	8
Acronym list	9
Appendix	10
Appendix 1: Definitions of learning disability	10
Appendix 2. Literature review methodology	11
References	12

Introduction

This literature review was undertaken as a part of the Learning Disabilities Needs Assessment which includes high quality relevant research reviews and policy documents from charitable and authoritative organisations detailing best practice and interventions supporting people with learning disabilities (LD).

Definitions used for LD are provided in Appendix 1 with the literature search strategy in Appendix 2.

The key recommendations from national policy documents since 2014 (the date of the last Suffolk LD needs assessment) are summarised below.

The NHS Long Term Plan 2019

The NHS Long Term Plan¹ contained twenty-one detailed recommendations related to services and support to those with learning disabilities by helping to:

- Gain control over their lives through personal budgets and housing opportunities
- Increase self-esteem through increased access to volunteering and employment
- Improving the quality of services available through reasonable adjustments so that they are more appropriate, digital flags on records so that professions are aware of the learning disability, proactive and timely support, regular general screening including assessment of vision, hearing and dental needs, access to lifestyle interventions such as smoking cessation
- Invest in crisis and forensic support
- Invest into facility for specialist staff training
- Monitor services with a view to system improvement

Care and Support Statutory Guidance²

Key recommendations relevant to people with learning disabilities set out in this guidance include:

- Services need to be person centred with reasonable adjustment to the communications so that information available, they are involved and express their views in the assessment of their case
- Crisis are prevented through early intervention (e.g. in managing money or addressing challenging behaviour)
- Supported through the transition from regular education with help in gaining employment, accessing the most appropriate housing, and establishing a social network with carers needs also considered

Interventions and recommendations for best practice in social care provision are summarised below.

An outcome and improvements framework³ commissioned by the Local Government Association (LGA) and Association of Directors of Adult Services (ADASS) sets out six interrelated elements in supporting adults with learning disabilities to live safe, well and fulfilled lives:

- Inclusion in local communities and to be treated with dignity and respect
- Equal access to services and opportunities
- Person-centred planning and support
- Safeguarding
- Sustainable modes of support
- Enabling progression, recognising the potential to progress and develop

Recommendations from the literature on specific aspects of provision are outlined below.

Informed choices and personalisation of care provision

- Provision of accessible information on available social care provision, enabling informed choices about care
- An annual review to assess care and support needs and provide the opportunity to change support options based on needs and preferences
- Availability of personal budgets and direct payments, with support to use direct payments
- A single point of contact or 'named worker' for queries and support⁴
- Joint working to meet the needs of service users

Housing needs and recommendations for support

The literature on learning disabilities indicates that best practice is to:

- Provide a range of housing options, including small-scale shared housing and self-contained units to enable choice and age-appropriate options⁴
- Enable people with learning disabilities to live close to family and social networks if they choose to, and provide the option of living independently for those it is suitable for⁴
- Provide accessible information to enable those with learning disabilities to make informed choices about their housing⁴
- Maintaining records of the housing status of people with learning disabilities⁵
- Surveying people with learning disabilities in the local authority area to understand their housing needs and preferences, and collecting feedback from tenants with learning disabilities to ensure that accommodation meets their needs⁶
- Local authority housing plans should address provision of current and predicted accommodation needs of people with learning disabilities⁵

Day services, activities and community provision for adults with LD

Social isolation is widely recognised as a significant challenge for many people with LD. A 2016 systematic review found that person-centred planning, alteration of activity patterns, supported learning programmes and semi-structured group sessions, including exercises that incorporate learning objectives and taught social skills were effective in reducing isolation⁷.

Key recommendations and evidence from the literature relating to provision for adults with learning disabilities in this area include:

- Reduce social isolation via provision of a range of age-appropriate, accessible activities catering for a range of interests
- Provide skills-based activities to support employment prospects
- Co-produce services and activities with the individuals accessing the services as far as practicable
- Facilitate and enable activities that can nurture genuine friendships between people with learning disabilities⁷

Access to leisure services and activities

A 2019 systematic review showed that care farms (also known as social farms) have supported people with learning disabilities with independence and social integration, physical health and general wellbeing, which in turn can lead to an improved quality of life⁸.

There is an emphasis in some recent literature on the importance of incorporating physical activity into services and activities provided for both children and adults with learning disabilities. The benefits from measures to increase physical activity include a reduction in the risk of comorbidities associated with learning disabilities, and an increase sense of wellbeing and control for many individuals. Measures to increase physical activity in the literature included incorporating activity planning into health and care plans, raising awareness of the importance of activity among carers, and providing accessible opportunities to access sport and leisure. These might include tailored, sociable activities encouraging initial participation, and reasonable adjustments to enabling people with learning disabilities to access mainstream leisure facilities^{9, 10}.

A specific need recently reported in the media, is the shortage of opportunities for people with learning disabilities to socialise in the evening, and the desire to 'stay up late' as part of a normal life¹¹. This highlights the need for a range of social opportunities including informal evening events.

Personal budgets and direct payments

Self-directed support is an approach to social care where care recipients are central to the decision-making process, and this approach had led to personal budgets and direct payments. A systematic review showed that while self-directed support is not accessible to all with a learning disability, it can lead to improved quality of life¹². A recent qualitative study based on the experience of family carers managing personal budgets found that families often found budgets stressful and hard to manage, but with adequate support and clear guidelines found that use of personal budgets were beneficial to wellbeing and offered sustainable arrangements for their family members¹³.

Employment support

Data from a 2005 national survey also shows the majority of people with learning disabilities would like to work¹⁴, and there is more recent evidence to show the benefits of employment both for people with learning disabilities and to employers. Paid work can bring physical and mental health benefits for the individual, build confidence, providing social networks, and leading to greater financial security, providing independence and choice¹⁵. Benefits for employers included increased staff morale, increased productivity among other staff and reputational benefits¹⁶.

Best practice outlined in the literature includes:

- Employment specialists working with people with learning disabilities in a person-centred planning approach, taking into account individual preferences and needs
- Record employment outcomes for people with learning disabilities, including salary and number of hours, for monitoring and reporting to the health and wellbeing board
- An employment strategy should be in place for people with learning disabilities, which should include the transition planning with young people with learning disabilities having access to employment agencies via their school or educational institute, and vocational training should be provided alongside education

Two recent examples of good practice are provision of supported internships in workplaces undertaken by young people aged 16-24 as part of a study programme¹⁷, and Project Search¹⁸. Project Search is a supported internship programme led by businesses where participants learn skills over the course of a year. An evaluation found that 36% of participants gained full-time employment with the hosting business.

Safeguarding

People with learning disabilities are vulnerable to abuse, harassment, neglect and being the targets of criminal exploitation. These vulnerabilities highlight the need for suitable safeguarding arrangements across organisations. The UK Government's Care and Support Statutory Guidance outlines requirements from the Care Act 2014¹⁹ for relevant organisations in undertaking these arrangements and include the following:

- All relevant organisations should have information sharing arrangements in place setting out process and principles for sharing information between each other, with other professionals and the local safeguarding board.
- Employers ensure that all staff including volunteers are training in recognising signs of abuse and neglect
- Local authorities may choose to undertake safeguarding enquiries for people where there is not a section 42 enquiry duty if it proportionate to do so, and will enable the local authority to promote the person's wellbeing and a preventative agenda. The Care Act 2014 (Section 42) requires that each local authority must make enquiries, or cause others to do so, if it believes an adult is experiencing, or is at risk of, abuse or neglect.

Provision for children and young people with learning disabilities

Each local authority area should publish a SEND 'Local offer', detailing the resources available for children and young people with special education needs. This information should be readily accessible to parents, and the information contained should be kept up to date²⁰.

The NICE Guidance recommends the provision of the following services for children and young people and their families:

- Portage services for pre-school children and childcare options that meet the needs of children with learning disabilities
- Short Breaks and Family placements
- Support groups for family carers, siblings and for young people with learning disabilities
- An independent information, advice and support service, and a single point of contact for practical information, support and signposting
- Opportunities for children and young people with LD to meet up and socialise, and provision of community activities that reflect preferences, choices and abilities

For children and young people with LD and behaviour that challenges, NICE recommends²¹:

- Services in the community such as education, general and specialist learning disability support to support families to care for their children as an alternative to residential placements
- Specialist behavioural support in the community including from Child and Adolescent Mental Health Services (CAMHS) practitioners for children with LD and behaviour that challenges
- Joint working between social care, education, health and behavioural services to develop skills for independence and maximise life opportunities
- Provision of residential placements commissioned as close to home as possible

Transition to adult services

The transition from childhood to young adulthood is recognised as a time that can be particularly challenging for young people with learning disabilities and worrying for their families²². Reviews undertaken of available qualitative studies reveal the anxieties of parents over this period, highlighting the need for access to support and guidance for family members²³.

A rapid evidence review undertaken in 2018 looked at the needs of young people around the time of transition across the areas of education and training, employment, housing and health and social care use²⁴. The authors found a shortage of available evidence around housing needs for this age group but recorded key findings relating to education, employment and health care provision. The literature reviewed emphasised the need for person-centred planning around all aspects of transition, involving the young person at all stages. In relation to education, the literature identified families and the wider family network as being key to successful transition planning. Transition outcomes were improved when career services were proactively involved in schools, and where schools had developed relationships with employers in their area to help facilitate work placements. The review authors also reported evidence that self-determination skills, developed via training in educational settings supported positive outcomes. The authors found supported employment, and mentors or peer mentors supported positive outcomes in relation to employment.

Similar best practice guidelines for transition have been developed by NICE²⁵ for this age group:

- Facilitate the full participation of young people with learning disabilities in their transition into adulthood so that they may express their preferences to the limit of their mental capacity
- Plan for transition from the age of 13 to 14 to encompass all aspects of adult life
- Take a person-centred approach with the young person as an active partner in the planning
- Review plans annually
- Children's and adults' services should actively work together for a smooth transition

Staff training

Key recommendations in the NICE Guidance relating to recruitment and training for staff working with people with learning disabilities include the provision of initial and ongoing training that covers the physical, mental, and sensory needs of this group, in addition to safeguarding reporting and the application of the Mental Capacity Act^{4,26}. The guidance also recommends that as far as possible, people with learning disabilities are involved in the recruitment process.

Guidance and recommendations for best practice for supporting people with learning disabilities during the COVID-19 pandemic

The available guidance for care workers and personal assistants supporting adults with learning disabilities during the pandemic emphasises the clinical vulnerability of this cohort and sets out the extensive infection prevention and control procedures expected of the care sector^{27, 28}. In addition, the guidance also outlines measures for supporting people with learning disabilities to understand the pandemic and to mitigate the impacts of the pandemic restrictions to help combat anxiety and social isolation.

The guidance emphasises the need for clear communication and recommends the use of easy-read and other accessible resources to explain restrictions. It also suggests keeping to regular routines, keeping contact with staff consistent and enabling people with LD to continue to do what they enjoy as far as possible. The guidance also emphasises the importance of carers taking care of their own health and wellbeing.

Best practice for Health Services in meeting the needs of people with learning disabilities

Key recommendations from the 2020 NHS England and Improvement Guidance for supporting people with learning disabilities included the following:

- Train staff to avoid diagnostic pitfall in managing patients with learning disabilities
- Develop systems to improve access to appropriate care (such as 'healthcare passports') and minimise adverse impact of hospital admissions on mental and emotional health
- Make all necessary reasonable adjustments to communicate with and involve service users and carers in decisions, including use of specialist such as liaison nurses for the learning disabled

Under the Equality Act 2010, public sector organisations are required to provide reasonable adjustments to ensure that services are accessible to people with disabilities. For people with learning disabilities accessing health care this may mean clear and simple explanations of what is happening and treatment options, help with attending appointments and help with managing issues of consent in line with the Mental Capacity Act²⁹.

Interventions and recommendations for best practice to reduce specific health inequalities

Annual health checks

Annual health checks for people with learning disabilities aged 14 and over are considered by experts a key intervention for health promotion and a mechanism for identifying symptoms and preventing avoidable deaths³⁰.

Cancer screening

Evidence of interventions that promote uptake of cancer screening include provision of easy-read materials and video resources to explain the screening process, and identification of people with LD at the time of invitation to enable provision of reasonable adjustments. The above steps require communication between services to allow for timely identification of people with LD and tailoring of materials and appointments to meet their needs. Public Health England (PHE) guidance for supporting women with learning disabilities to access breast screening states that GP practices should inform the local breast screening service about eligible women with learning disabilities to enable reasonable adjustments to be put in place³¹. The literature emphasises the need to raise awareness of the importance of cancer screening among people with LD and their carers, enabling them to make informed choices about attending screening³². Recommendations for best practice include the involvement of providers, promotion at events for people with LD and discussion of screening at annual health checks³³.

Flu vaccination uptake

Expert authorities recommend targeting communication to reach people with learning disabilities and their carers explaining the importance of getting the flu jab to improve uptake in this group.

Priorities for GP surgeries include identifying people with learning disabilities and marking them as being eligible for flu vaccines on learning disability registers, and provision of reasonable adjustments at appointments such as

offering appointments at quiet times and offering longer appointments, in addition to offering nasal spray options as an alternative to injections³⁴.

Mental health outcomes

Expert opinion suggests that interventions to help carers recognise the symptoms of mental ill-health, and an understanding of where to seek support may improve mental health outcomes³⁵. NICE Guidelines state that services supporting people with learning disabilities should provide training for staff to be aware of the increased risk of mental ill-health, and know where to refer people with learning disabilities and suspected mental ill-health.

Dementia

Early symptoms of dementia in people with LD often go unnoticed or are attributed to challenging behaviour. NICE Guidance emphasise the importance of formal and informal carers recognising the early signs of dementia, and it is recommended that a dementia pathway specifically for this group is in place to improve outcomes²⁶.

Dental health outcomes

UK Government Guidance sets out key recommendations for carers of people with LD and dental practices to meet the oral health needs of people with LD. These include provision of reasonable adjustments in dental practices such as longer appointments, appointments at quiet times, and the availability of easy-read and visual materials explaining procedures³⁶. The guidance cites anxiety around procedures as an importance consideration, and provision of additional resources, time and appropriate training for staff are recognised as being key to reducing this anxiety. The guidance also emphasises the importance of providing materials for carers to outline the importance of oral hygiene.

Weight management and increasing physical activity levels

Public Health England have identified people with LD as a priority group for access to weight management services, recommending that where possible reasonable adjustments are made enabling attendance at mainstream services³⁷. Expert recommendations also include increasing awareness among people with learning disabilities and their carers about the importance of physical activity, incorporating measures to increase physical activity in care and support plans, and improving accessibility of leisure centres.

Diabetes care and prevention of diabetes

The NHS RightCare Pathway for providing support to people with learning disabilities emphasises the importance of person-centred planning for patients with diabetes and a learning disability, and appropriate staff training to support diabetes patients with additional needs³⁸. The pathway document also recommends that weight management and lifestyle programmes accommodate people with learning disabilities to attend with their carers, and the importance of carers supporting self-management of diabetes among people with learning disabilities. The document also recommends referral to adapted Diabetes Prevention Programmes, or mainstream programmes where reasonable adjustments can be made such as attendance with carers.

Access to relationship education and sexual health services

Mencap reports on the barriers and enablers to people with learning disabilities developing and sustaining relationships³⁹. In their review of recent research, they summarise that receipt of inaccurate or incomplete information on sex and relationships means that people with learning disabilities may be at higher risk of negative sexual experiences, contracting sexually transmitted diseases or unwanted pregnancies. They emphasise the need for people with learning disabilities to receive accessible and appropriate education on sex and relationships, including visual materials. They also emphasise the need for information and education programmes on sex and relationships to be co-designed with people with learning disabilities.

End of life care and bereavement support

A briefing on experiences of grief by people with LD outlined how grief may be expressed differently if not felt the same by people with LD. The briefing stated the importance of involving people with LD in conversations about grief, and where appropriate, providing access to dedicated counselling⁴⁰.

Glossary

The below list provides definitions and descriptions of terms used in this report. Where definitions from other sources are used, references to these sources are provided.

Day services -services provided by the social services, the NHS and other voluntary organisations and can encompass a range of activities and facilities that serve to benefit the people that attend them. These include day centres providing care and activities and social opportunities.

Direct Payment – an amount of money paid by the local council or NHS Trust to a client or their care carer to meet a client’s needs.

Education, Health and Care (EHC) Plan – An EHC plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social need and set out the additional support to meet those needs⁴¹.

Learning disability – Generally defined by the presence of a significantly reduced ability to understand new or complex information or to learn new skills, a reduced ability to cope independently, and an impairment that started before adulthood, with a lasting effect in development.

Learning difficulty- Constitutes a condition which creates an obstacle to a specific form of learning but does not affect the overall IQ of an individual⁴².

Personal budget – The amount of money paid by the local council towards social care and support.

Profound and multiple learning disabilities (PMLD) - A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent⁴³.

Special Educational Needs (SEN) - when a child has a learning difficulty or disability which calls for special educational provision to be made for him or her⁴⁴.

Special Education Needs and Disabilities (SEND)- Defined by the NHS as a learning difficulty and/or disability that means that special health and educational support is required⁴⁵.

Settled accommodation – secure, medium to long-term accommodation.

Severe learning disabilities – Someone with a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing washing, eating and keeping safe, have difficulties with social skills and need life-long support⁴⁶.

Supported living – a service designed to help people with a wide range of support needs retain their independence by being supported in their own home⁴⁷.

Unsettled accommodation – accommodation where the resident has no or low security of tenure/residence

Working aged adults – adults aged 18-64.

Acronym list

ACS – Adult and Community Services
ASD – Autism Spectrum Disorder
CAMHS- Child and Adolescent Mental Health Services
CCG- Clinical Commissioning Group
CiC – Children in Care
CYP - Children and Young People
DCYP- Disabled Children and Young People
ICD-10 – International Classification of Diseases, Tenth Revision
IESCCG – Ipswich and East Suffolk CCG
IQ – Intelligence Quotient
IWS- Independence and Wellbeing Service
LD- Learning Disabilities
LD&A – Learning Disabilities and Autism
LeDeR – Learning from deaths of people with a learning disability
LGA – Local Government Association
MiA – Moving into Adulthood
NICE - National Institute for Health and Care Excellence
NDTi – National Development Team for Inclusion
NSFT -Norfolk and Suffolk Foundation Trust
PANSI -Projecting Older People Population Information System
POPPI – Projecting Older People Population Information
PHE- Public Health England
PWLD- People with Learning Disabilities
QOF- Quality Outcome Framework
SALT- Speech and Language Therapy
SCC- Suffolk County Council
SNNs- Statistical Nearest Neighbours
SPLD – Specific Learning Difficulties
YP- Young Person

Appendix

Appendix 1: Definitions of learning disability

While the term 'learning disability' can mean different things to different people, and is used differentially across English-speaking countries, in the UK, the term learning 'Learning disability' is generally defined by the presence of:

- A significantly reduced ability to understand new or complex information or to learn new skills
- A reduced ability to cope independently
- An impairment that started before adulthood, with a lasting effect in development⁴⁸

Learning disabilities have previously been defined according to ICD-10 classifications and can be defined based on estimation of IQ score and the presence of a medical diagnosis⁴⁹. When addressing the wider needs of people with learning disabilities, it is generally accepted and legislated under the Care Act² that provision of support should not be based on a medical diagnosis. It is therefore important to note that individuals recorded as having a learning disability as a support need by local authorities and providers may not have a diagnosis of a learning disability in their medical records.

Learning disabilities are lifelong conditions, and can be classed as mild, moderate, severe, or profound and multiple⁵⁰. Descriptions of these categories of learning disability are outlined below:

- Mild learning disabilities: A person who is said to have a mild learning disability is usually able to hold a conversation and communicate most of their needs and wishes, and are often independent in caring for themselves and doing everyday tasks. They may need some support with understanding complex ideas and with tasks such as budgeting and completing forms. People with mild learning disabilities often go undiagnosed.
- Moderate learning disabilities: People with a moderate learning disability are likely to have some language skills that mean they can communicate about their day to day needs and wishes. People may need some support with caring for themselves, but many will be able to carry out day to day tasks with support.
- Severe learning disabilities: A person with a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities, have difficulty with social skills and need life-long support
- Profound and multiple learning disabilities: A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent

The needs of an individual with a mild learning disability will differ significantly from those with a severe or profound learning disability, therefore it is important to understand the differences in need among this cohort and the implications for providing support and services.

It is important to note that in the UK, mild and moderate learning disabilities have different meanings in education services and in health services when describing the needs of children and young people. The term 'Special educational needs and disability' (SEND) is used to refer to the needs of a child or young person if they have a learning difficulty and/or disability that means they need special health and educational support⁴¹. The categories of 'Severe' and 'Profound' learning difficulty as used in SEND guidance broadly align with the categories of severe and profound learning disabilities outlined above⁵⁰.

The term 'learning disabilities' is distinct from the term 'learning difficulties', which is used in the UK to define a condition which creates an obstacle to a specific form of learning but does not affect the overall IQ of an individual. It is however important to acknowledge that an individual may have both a learning disability and a learning difficulty.

Appendix 2. Literature review methodology

National policy review: A pragmatic search was undertaken of the Gov.uk and NHS websites for relevant national policy documents, in addition to a review of reports and other publications from national organisations supporting people with learning disabilities.

Evidence review: A list of search terms was devised, designed to retrieve information on learning disabilities and health, housing, education and social care service is use in order to understand inequalities and evidence for best practice. These search terms were based on those used in an evidence review undertaken as part of the Hackney Adult Learning Disability Needs Assessment in 2016 (cite). These search terms were used to search the NHS Evidence database. This database was chosen as it contains content from a range of archives including Cochrane libraries, Social Care Online, GOV.UK, the Royal Colleges and Clinical Knowledge Summaries, therefore content aligns with our objectives to understand both health and social needs of people with learning disabilities.

The search terms used in the evidence review as entered into the NHS Evidence Database are outlined below:

Health search:

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND ("health care*" OR "healthcare" OR "health service*" OR healthservice* OR "health support" OR "health and social care" OR "health protection" OR "health promotion" OR "wellbeing" OR "wellness" OR "medicine" OR "medical" OR "clinic*")

Housing search:

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND (Hous* OR "Social Hous*" OR Rent* OR "Private Rent*" OR "Social* Rent*" OR Home* OR Homeless* OR "Rough sleep*" OR shelter* OR residenc*)

Employment search:

("Learning disabilit*" OR "Learning difficult*" OR "Intellectual disabilit*" OR "special education* need" OR "SEN" OR "S. E. N." OR "S.E.N." OR "Mental retardation" OR "Mental Handicap*") AND (job* OR employ* OR work* OR career* OR unemploy*)

Additionally, a list of simplified search terms were used to gather information on specific health needs. These search terms were entered into both the NHS Evidence database and Google.

-Learning disability dental

-Learning disability mental health

-Learning disability flu vaccine

-Learning disability screening

Given limitations on time and resources, the main focuses of our review were key policy and guidance documents and secondary research papers. Reports and articles from 2014 onwards were reviewed, to reflect the timing of the last needs assessment, although where key references predating 2014 were cited within other papers or by organisations representing those with learning disabilities, information from these references was included. As the term 'learning disability' is often used in North America to refer to what would be termed in the UK as 'learning difficulty', our focus was primarily on literature from the UK.

Limitations: The results of this evidence review were based on a pragmatic search of the available literature with limited resources. It is therefore possible that some recommendations were missed in our search. Similarly, the vast majority of literature available pre-dates the start of the COVID pandemic therefore there is limited evidence and data relating to provision for this cohort during the pandemic.

References

1. NHS. *The NHS Long Term Plan*. (2019).
2. Department of Health and Social Care. Care and support statutory guidance. (2021).
3. Local Government Association. Supporting adults with learning disabilities to have better lives. (2021).
4. National Institute for Health and Care Excellence. Learning disabilities and behaviour that challenges: service design and delivery (NICE Guidance NG93). (2018).
5. Mencap. Housing for people with a learning disability. 1–50 (2012).
6. The Housing and Support Partnership. *Planning and Commissioning Housing for People with Learning Disabilities: A Toolkit for Local Authorities*. (2010).
7. Howarth, S., Morris, D., Newlin, M. & Webber, M. Health and social care interventions which promote social participation for adults with learning disabilities: a review. *Br. J. Learn. Disabil.* **44**, 3–15 (2016).
8. Murray, J. *et al.* The impact of care farms on quality of life, depression and anxiety among different population groups: A systematic review. *Campbell Syst. Rev.* **15**, (2019).
9. Hallawell, B., Stephens, J. & Charnock, D. Physical activity and learning disability. *Br. J. Nurs.* **21**, 609–612 (2012).
10. McKenzie, K., Murray, K. & Murray, G. Encouraging physical activity in people with learning disabilities. *Nurs. Times [online]* **114**, 18–21 (2018).
11. Stay up Late. Adults with learning disabilities should be able to go out and stay up late. (2021).
12. Harkes, M. A., Brown, M. & Horsburgh, D. Self Directed Support and people with learning disabilities: a review of the published research evidence. *Br. J. Learn. Disabil.* **42**, 87–101 (2014).
13. Turnpenny, A., Rand, S., Whelton, B., Beadle-Brown, J. & Babaian, J. Family carers managing personal budgets for adults with learning disabilities or autism. *Br. J. Learn. Disabil.* **49**, 52–61 (2021).
14. NHS Digital. Adults with Learning Difficulties in England, 2003-2004. (2005).
15. Mencap. Employment - what we think. (2016).
16. Beyer, S. & Beyer, A. A systematic review of the literature on the benefits for employers of employing people with learning disabilities. *Mencap* (2017).
17. Department for Education. Providing supported internships for young people with an EHC plan. (2013).
18. Kaehne, A. *Final Report: Evaluation of Employment Outcomes of Project Search UK*. (2014).
19. Department of Health and Social Care. New measures to improve care for people with autism and learning disabilities. (2019).
20. Mencap. The Local Offer. (2021).
21. National Institute for Health and Care Excellence. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NICE Guidance NG11). (2015).
22. Young-Southward, G., Philo, C. & Cooper, S.-A. What Effect Does Transition Have on Health and Well-Being in Young People with Intellectual Disabilities? A Systematic Review. *J. Appl. Res. Intellect. Disabil.* **30**, 805–823 (2017).
23. Codd, J. & Hewitt, O. Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective. *Br. J. Learn. Disabil.* **49**, 39–51 (2021).
24. Kaehne, A. *et al.* Rapid Review Transition for young people with learning disabilities in housing , social care , and health care , education / training , and employment. 1–35 (2018).
25. National Institute of Health and Care Excellence (NICE). Transition from children’s to adults’ services for young people using health or social care services. <https://www.nice.org.uk/guidance/ng43> (2016).
26. National Institute for Health and Care Excellence. Learning disability: care and support of people growing older (NICE Quality Standard 187). (2019).
27. Department of Health and Social Care. Coronavirus (COVID-19): guidance for care staff supporting adults with learning disabilities and autistic adults. (2021).
28. Social Care Institute for Excellence. COVID-19 guide for care staff supporting adults with learning disabilities or autistic adults. *Coronavirus (COVID-19) advice for social care* (2020).
29. Public Health England. Reasonable adjustments: a legal duty. (2020).
30. Public Health England. Annual health checks and people with learning disabilities: guidance. (2016).
31. Public Health England. Supporting women with learning disabilities to access breast screening. (2021).
32. Byrnes, K. *et al.* Attitudes and perceptions of people with a learning disability, family carers, and paid care workers towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation. *Psychooncology.* **29**, 475–484 (2020).
33. Public Health England. Population screening: reducing inequalities for people with a learning disability, autism or both. (2021).
34. Public Health England. Flu vaccinations: supporting people with learning disabilities. (2018).
35. National Institute for Health and Care Excellence. Mental health problems in people with learning disabilities: prevention, assessment and management NICE guideline [NG54]. (2016).
36. Public Health England. Guidance: Oral care and people with learning disabilities. (2019).

37. Public Health England. Obesity and weight management for people with learning disabilities: guidance. (2020).
38. Kachika, J. *NHS RightCare Pathway: Diabetes. Reasonable adjustments for people with a learning disability who have diabetes.* (2017).
39. Mencap. Sexuality - research and statistics. (2021).
40. Read, S. Supporting bereaved people with learning disabilities.
41. UK Government. Children with special educational needs and disabilities (SEND). *Children with special educational needs and disabilities (SEND)* (2016).
42. Mental Health Foundation. Learning disabilities. (2021).
43. NHS. Learning Disabilities Overview. (2018).
44. Department of Education & Department of Health. Special educational needs and disability code of practice: 0 to 25 years. *Government policies Educ. Heal.* 292 (2015).
45. NHS England. Special educational needs and disability (SEND). *Homes not Hospitals* (2020).
46. The Challenging Behaviour Foundation. What is a Severe Learning Disability? (2021).
47. Dimensions. Supported Living. (2021).
48. Department of Health. Valuing People: A New Strategy for Learning Disability for the 21st Century. 1–149 (2001).
49. National Institute for Health and Care Excellence. *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges: SCOPE.* (2012).
50. National Association of Disability Practitioners. Definitions of learning disability and learning difficulties. *Understanding the nature and characteristics of learning disability.*