



Factsheet 8: Specialist services for people with learning disabilities

Key considerations for reviewers

- Did the person have full access to generic health and social services where available?
- Did the person have access to specialist health, social and commissioned residential, personal care or support if required?
- Did the young person have a coordinated and smooth transition plan that supported their health and social care transition between child and adult services?
- Did the person have complex health needs and receive additional health funding through Continuing Healthcare (CHC)? Was this well managed?
- Had the person's needs been assessed under the Care Act 2014? Was the person and their family involved in the assessment and was an advocate involved if appropriate? Did any support package meet their needs? Was any support package regularly reviewed?
- Was there an integrated approach between health and other services and supports?
- Were the guiding principles underpinning all service provision (rights, independence, control, inclusion) upheld?

Introduction

People with learning disabilities should be able to access primary and secondary health services, including health promotion and cancer screening in the same way as the general population. Due to the different and enhanced needs of people with learning disabilities, Clinical Commissioning Groups (CCGs) commission additional specialist health support specifically for people with learning disabilities, through Community Learning Disability Teams (CLDTs). Additional individualised funding and support for those people with the most complex health needs may also be commissioned and provided through a Continuing Healthcare Fund (CHC).

Across England there is great inconsistency in the way that specialist services and wider services for people with learning disabilities are commissioned and delivered. CLDTs may be health only or include social care practitioners if they are joint funded, being jointly commissioned by the local authority. However they are commissioned, all services should demonstrate person centred care that works in partnership with families and providers, is well coordinated across multiple agencies, cost effective and delivered using a seamless approach to care.

Local authorities often commission a wide range of different providers to meet the housing, personal care and social support needs of people with learning disabilities across their geographical area. In commissioning this care local authorities are also responsible for monitoring and measuring the quality of care delivered, commissioning independent advocacy services, where required, to help support clients in highlighting any unmet needs or in raising delivery concerns.

Local authorities and CCGs are required to undertake a Joint Strategic Needs Assessment (JSNA), often undertaken by public health teams who are employed by local authorities, to collect and publish evidence on the demographic information and needs of all populations living in their local areas. JSNAs should



include information on the numbers and needs of people with learning disabilities, with links to any additional information collected nationally for local areas, which is collected and published nationally by the Learning Disabilities Observatory. In addition to government reports, all best practice guidance to support findings and issues that arise from this evidence for people with learning disabilities are issued by the Learning Disabilities Observatory. This evidence should guide all service commissioning intentions, including primary, secondary and specialist health services and social care provision (such as housing, employment and leisure services).

The four guiding principles underpinning service provision

The four guiding principles that should underpin all services for people with learning disabilities are:

- Rights
- Independence (having as much choice and control as possible over the support needed)
- Control (being involved in, and in control of, decisions made about the person's life)
- Inclusion (being able to participate in all aspects of community, and have the support to do so).

Specialist learning disability services support these principles by striving to reduce the health inequalities experienced by people with learning disabilities. They aim to minimise the impact of:

- Exposure to social determinants of poorer health such as poverty, poor housing, unemployment, social isolation and lack of personalised, meaningful activity
- Health problems – including those associated with specific genetic and biological conditions associated with learning disabilities
- Personal health risks and behaviours such as self-harm, poor diet and lack of exercise
- Communication difficulties and reduced understanding of health issues (health literacy)
- Deficiencies related to access to healthcare provision.

Specialist health services

Children and Young People

Special Education Needs (SEN) and Disability/Education, Health and Care plans (EHC plans) - From September 2014, the Special Education Needs System underwent reforms. The current system now encompasses continuous support throughout a person's educational life (from birth to 25 years) instead of the previous system which offered post 16 support under a separate system. Children and young people with complex support needs may have an Education, Health and Care (EHC) plan. EHC plans encompass support for education, health and social care for young people up to the age of 25. Local authorities are responsible for compiling a plan or 'local offer' which provides information about locally available and out-of-area specialist provision. This may include provision of some children's services continuing up until the age of 25 years.

Children's Learning Disability Nursing Services assess and manage the health needs of children and young people aged 0-18 years with moderate to severe learning disabilities and additional health needs. Children and young people must be registered with a local GP to receive this service.



Child and Adolescent Mental Health Service Learning Disability Teams (CAMHS LD) offer specialist psychological, emotional and behavioural support for children with learning disabilities. CAMHS LD teams comprise:

- Consultant child and adolescent psychiatrist
- Clinical psychologists
- Nurses and learning disability practitioners
- Counsellors for parents
- Social worker/family therapist

Children with more complex needs may need support from the **Specialist Services for Children with Learning Disabilities (SSCLD)**. Specialist Services for Children with Learning Disabilities (SSCLD) are part of wider networks of health, education and social services. SSCLDs support children and young people with moderate, severe and profound learning disabilities up to the age of 18 (19 if in full-time education). SSCLDs become involved with supporting children once a Community Child Health Team has completed an assessment of the child's needs and his/her diagnostic and developmental status. SSCLDs comprise:

- Specialist community learning disability nurses and support workers
- Clinical psychologists
- Consultant child and adolescent learning disability psychiatrist
- Primary mental health specialist for children with learning disabilities

Transition from Children's to Adults' Services

Up until the age of 18 (19 if in full-time education) the responsibility of care for children and young people with learning disabilities resides with child health and social care services. Between the ages of 16 and 19, the 'transition' period begins, with planning for the transfer of support to adult services. In some areas, **Specialist Transition Teams** sit within learning disability teams and provide transition support for young people with learning disabilities aged 16-19.

Adult Services

Social care - There is variation nationally in how social services are provided to adults with learning disabilities. Some local authorities provide specialist learning disability social work teams while others have joint health and social care teams and others provide generic adult social work teams. All local authorities are required under the Care Act 2014 to assess the needs of people who may require support and to provide services to meet eligible needs. These services are accessed via local councils.

Adult Community Learning Disability Teams (CLDTs) are multidisciplinary teams that offer services to adults (18 years and above) who have learning disabilities. There are a variety of models of CLDTs. They may comprise social workers, physiotherapists, occupational therapists, speech and language therapists, psychologists and psychiatrists, community nurses, music therapists and support workers. Some areas also include consultant nurses in the CLDT.

CLDTs can enable people with learning disabilities to access to other services and can provide specialist provision themselves. They can, for example, arrange support for people whose behaviour challenges or who have other health needs such as epilepsy or incontinence, in addition to identifying day services, respite services or long-term living options.



Health Facilitators - Primary care liaison nurses or health facilitators help people with learning disabilities to access primary care, and work with GPs and primary care staff to support people with learning disabilities. They play a key role in the implementation of reasonable adjustments for people with learning disabilities using primary care services and may support people with their annual health checks.

Acute Liaison Nurses work to improve mainstream hospital care for people with learning disabilities. Their role focuses not only on working directly with clinicians and patients, supporting care delivery and providing advice, but also on raising the profile of the support available to adults, through community teams and specialist services for this group.

Intensive Health Outreach Teams (IHOTs) work in collaboration with health and social care partners to provide assessment and treatment for adults with learning difficulties with associated health problems. This service is primarily community based and supports people with learning disabilities whose health needs require a greater level of intensity and specialist intervention than are provided by CLDTs.

Assessment and treatment inpatient services - Government policy is for a shift from inpatient to community-based services. People with learning disabilities in assessment and treatment inpatient services are having Assessment and Treatment Reviews with the aim of moving them to care options in their local community. Where active assessment and treatment is required for a time limited period, it should be as near to home as possible, person-centered and provide evidence-based assessment and treatment with demonstrable positive outcomes.

Specialist forensic services that support people who offend or are at risk of offending may be part of a CLDT, or a separate specialist service. In addition, prison liaison nurses are being introduced in some areas to ensure that people with learning disabilities receive good healthcare whilst in prison.

Specialist social care services

Advocacy services can support someone else to get their views across, and can offer useful, independent advice and support for people with learning disabilities and their families. They can help people with learning disabilities to speak up for themselves through self-advocacy.

Day service facilities offer a range of supported activities in the local community. These usually include a mixture of work, leisure and educational skills, for anyone over 16 who needs support. Some day facilities also offer evening and weekend activities.

Specialist housing options available for people with learning disabilities include:

- living independently, with support as required
- sharing a home with others, with regular or 24 hour support
- living in a nursing home, where staff can provide constant support for major health needs

The type of housing that would be suitable for a person depends on the individual themselves and their needs and preferences.

Short breaks (sometimes referred to as respite) provide people with learning disabilities and their families a change from their daily routine. They can offer new experiences for people with learning disabilities and give parents and carers a break from their role.

Leisure activities can offer people with learning disabilities a chance to learn new skills, improve their quality of life and raise their self-esteem. It also provides an opportunity for inclusion in the local community and the development and maintenance of friendships. There are many different types of



specialist leisure activities for people with learning disabilities, including specialist sports clubs, social groups and events. A number of agencies also provide specialist play equipment and toys for people with learning disabilities.

Employment support is offered to people with learning disabilities through Supported Employment agencies. These adopt a personalised approach to helping people to obtain and maintain employment.

The provision of 'reasonable adjustments'

Health and social care organisations have statutory responsibilities under the Equality Act 2010 and the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 to make 'reasonable adjustments' in how services are provided in order to reduce the preventable inequalities in health experienced by people with learning disabilities. Whilst all people with learning disabilities should be able to access generic health and social services, some specialist services for people with learning disabilities are also provided to minimise any health and social inequalities that people with learning disabilities experience. The guiding principles that should underpin all services for people with learning disabilities are rights, independence, control and inclusion.

Additional sources of information

Hoghton M, Turner S, Hall I. (2013) Improving the health and wellbeing of people with learning disabilities: an evidence-based commissioning guide for Clinical Commissioning Groups (CCGs)
<https://www.rcpsych.ac.uk/pdf/RCGP%20LD%20Commissioning%20Guide%202012%2010%2009%20FINAL.pdf>

NHS Choices Social Care and Support guide <https://www.nhs.uk/conditions/social-care-and-support-guide/>

SCIE Community-based day activities and supports for people with learning disabilities: How we can help people to 'have a good day?' www.scie.org.uk/publications/guides/guide16/

National Commissioning Board (2017) Commissioning Services for People with a Learning Disability Good Practice Guidance.
https://ipc.brookes.ac.uk/publications/Commissioning_for_People_with_Learning_Disability.pdf