Down Syndrome Act 2022 draft statutory guidance: DS CEN's response to the public consultation on 'the guidance'

About the DS CEN

The Down Syndrome CEN (DS CEN) is a group of 130+ speech and language therapists working with children and adults who have Down syndrome. This document was developed in response to the Down syndrome Act 2022 draft statutory guidance, by a working group of speech and language therapists from the DS CEN. It was endorsed and adopted by the CEN membership in March 2026.

About the Guidance

The Down Syndrome Act 2022 draft statutory guidance ('the guidance') sets out the steps that would be appropriate for relevant authorities in health, social care, education and housing services to take to meet the specific needs of people with Down syndrome in the exercise of their relevant functions. This is guidance given under the DS Act, and it contains:

- existing statutory duties (which must be complied with in any case)
- existing guidance
- examples of good practice when planning, commissioning and/or providing services and support to people with Down syndrome (see 'Annex: resources and examples of good practice' on the main consultation page)

Below is the information included in the draft guidance Section 2: High-quality and holistic healthcare, The health needs of people with Down syndrome https://www.gov.uk/government/consultations/down-syndrome-act-2022-draft-statutory-guidance/down-syndrome-act-2022-draft-statutory-guidance#high-quality-and-holistic-healthcare

The Down Syndrome CEN recommends the following additions to the guidance in red:

The Draft Guidance

The health needs of people with Down syndrome
It is important to take account of the particular health needs people with Down syndrome are likely to need support with, including co-occurring health conditions.
People with Down syndrome may have particular needs in relation to:

- cardiac issues such as heart disorders and defects that affect the normal working of the heart. Symptoms can include shortness of breath, chest pain, blue-coloured skin and nails, and getting tired easily. Around half of all children with Down syndrome are born with a heart condition
- respiratory issues - people with Down syndrome may be more vulnerable to having frequent respiratory infections, such as pneumonia
- gastrointestinal issues, such as issues with their airways and digestive system. Common problems include vomiting and diarrhoea, constipation, food intolerance, Hirschsprung's Disease, abdominal pain and difficulties with toilet training among children with Down syndrome

- conditions such as diabetes and thyroid disorders - these can cause symptoms such as tiredness, slow growth, weight gain, constipation, sensitivity to cold, hair loss, dry skin, diarrhoea and anxiety
- problems with their joints and muscles, which can cause pain and lead to issues with posture and mobility. This can be caused by several reasons, such as arthritis, low muscle tone, lax ligaments and hypermobile joints
- underlying neck instability - although significant damage caused by neck instability is rare and most people have mild early warning signs, it can result in paralysis and, in extreme cases, death (see reference 6)
- increased risk of infections and these infections can be more difficult to treat. People with Down syndrome also have a higher prevalence of autoimmune disorders, such as type 1 diabetes and coeliac disease
- issues with hearing, which can impact the development of speech, language, behaviour and social skills. Difficulties include conductive hearing loss due to glue ear and age-related hearing loss
- issues with their vision, such as short-sightedness, long-sightedness and astigmatism. There is also an increased incidence of disorders such as congenital cataracts, squint and glaucoma
- their teeth - this includes differences in the development and structure of teeth, which can lead to differences in oral and dental health. People with Down syndrome may also be more prone to gum disease
- screening for blood disorders - people with Down syndrome have a higher risk of developing blood disorders, including leukaemia (blood cancer), particularly in childhood
- dementia - Alzheimer's disease and symptoms of dementia affect adults with Down syndrome more frequently and the onset of dementia tends to occur earlier in life
- feeding, diet and weight gain and growth - people with Down syndrome may experience challenges with growth and being overweight, as well as difficulty accessing nutrition information and physical activities. Some studies show that people with Down syndrome have a slower metabolism, burn calories more slowly and store more fat (see reference 7). Feeding difficulties requiring management by speech and language therapy, often working as part of specialist feeding teams, must be available to from establishing infant feeding, managing transition from tube feeding, supporting the development of a range of eating and drinking skills to ensure access to a full and varied diet, and managing eating and drinking difficulties throughout the lifespan, including loss of skills associated with aging and/or dementia.
- sleep - including sleep-related breathing disorders (also known as sleep apnoea), difficulty settling, frequent night waking and parasomnias
- their mental health and wellbeing, such as with depression and anxiety. For example, typical features of depression in people with Down syndrome include sleep disturbance, weight loss and tiredness
- having multiple health conditions - Down syndrome is associated with an increased incidence of numerous co-occurring conditions. These can include autism, attention deficit hyperactivity disorder (ADHD), gastroesophageal reflux, infantile spasms and scoliosis
- an unexplained regression in their daily lives, such as their abilities to communicate, their sleep quality, and changes to their personality and behaviour

While the above health issues are well documented in relation to the needs of people with Down syndrome, it is critically important for healthcare professionals to recognise that these are by no means exhaustive. People with Down syndrome can have any illness, not just those illnesses or health needs more commonly associated with the condition. The primary objective must always be to ensure that a person with Down syndrome receives a comprehensive assessment that proactively considers biological, psychological and social factors currently influencing their presenting needs.

Designing and planning health services

Effective planning and leadership at a local system level are crucial to ensuring people with Down syndrome are able to access joined-up health, social care and education services. Health and care services must implement the reasonable adjustment digital flag as mandated by the Information Standard - further information on the flag and

reasonable adjustments can be found in section '1. Accessible and person-centred services' above. This will help ensure that resources are used effectively and that policies are implemented successfully.

Local authorities must promote the efficient and effective operation of a market in services for meeting care and support needs in their area - with a view to ensuring that people have a variety of high-quality services to choose from and the information to make an informed decision. In doing this, the local authority must have regard to various matters, including the current and future likely demand for services.

ICBs are NHS organisations responsible for planning and arranging health services for their local population. As strategic commissioners, ICBs focus on:

- providing system leadership for population health
- setting evidence-based and long-term population heath strategy
- working as healthcare payers to deliver this, maximising the value that can be created from available resources

Every ICB and its partner local authority (or authorities) with responsibility for commissioning social care must establish a statutory joint committee called the integrated care partnership (ICP), which may appoint additional members concerned with improving the health and care of the population. ICPs are joint committees formed between ICBs and their partner local authorities. ICPs are the convenors of partners in integrated care systems (ICSs), with the flexibility to appoint additional members from sectors such as housing, VCSE and social care.

ICPs have a statutory duty to prepare the ICS integrated care strategy setting out how commissioners in the NHS and local authorities - working with wider partners - can deliver more joined-up, preventative care. This includes addressing how health and care needs could be met more effectively through arrangements between NHS bodies and local authorities. ICSs are partnerships of organisations that:

- come together to plan and deliver joined-up health and care services
- improve the lives of people who live and work in their area

The Secretary of State for Health and Social Care has issued statutory guidance on the preparation of integrated care strategies to ICPs to help them develop their integrated care strategy, which they must have regard to.

System planning and leadership

Under the National Health Service Act 2006 (as amended by the Health and Care Act 2022), ICBs and their partner NHS trusts are required to produce a joint forward plan - updated annually - setting out how they will exercise their functions over the next 5 years, including the ICB's plans as a commissioner. In preparing their plan, they must have regard to the integrated care strategy prepared by the ICP and the joint local health and wellbeing strategies produced by local authority health and wellbeing boards (HWBs) having considered the local joint strategic needs assessment (JSNA). As part of this, ICBs are encouraged to consider the needs of people with Down syndrome in planning processes.

Section 26 of the Children and Families Act 2014 (the 'Children and Families Act') requires the local authority, ICB and NHS England to make arrangements about the education, health and care (EHC) provision to be secured for children and young people with SEN and those with a disability in their area. This must include arrangements for considering and agreeing the EHC provision reasonably required by the learning difficulties and disabilities that result in children and young people with SEN, and by the disabilities of children and young people in their area. It does not specify the form that the arrangements should take - this should be agreed locally.

ICBs, as the local leaders and commissioners of many NHS services, are well placed to work across local NHS services and support them to meet the needs of people with Down syndrome. In the NHS, ICBs are the organisations responsible for planning and purchasing healthcare services for their local population.

Commissioners should make use of information about the health needs and incidence of co-occurring conditions for people with Down syndrome when discharging their wider duties to plan, commission and provide services for people in their area. In practice, this means commissioners having a good understanding of the number of people with Down syndrome in the local area, and considering what needs they may have, to effectively commission appropriate services.

It is up to partners in each local area to agree how they will do this. As set out in appendix 1 of NHS England's Guidance on developing the joint forward plan, ICBs and partner trusts have a duty to involve people and communities in decisions about the planning, development and operation of the services they commission and provide. ICBs must also enable patients to make informed choices about the health services available to them.

To identify and predict how area needs may change over time, local authorities and ICBs should use:

- demographic data
- population health data, including data from primary care, secondary care and acute services
- social care data
- insights they gather from engagement with people with Down syndrome, and their families and carers

For example, improvements in care have resulted in significantly improved life expectancy for people with Down syndrome (see reference 4). A growing number of people with Down syndrome are therefore expected to outlive their parents, which is likely to result in more people requiring additional support later in life as their parents become less able to support them (see reference 8).

Executive leads on integrated care boards

NHS England published statutory guidance on Executive lead roles within integrated care boards in May 2023, which says that every ICB should identify a member of its board to lead on supporting the ICB to perform its functions effectively in the interest of the following population groups:

- children and young people (aged 0 to 25)
- children and young people with SEND
- safeguarding of children and adults
- learning disability and autism (all ages)
- Down syndrome (all ages)

These executive leadership roles are added to the statutory requirement for each ICB to include at least one mental health lead.

The guidance makes clear that every ICB should identify a member of its board who has explicit responsibility for people with Down syndrome of all ages. The executive lead will support the ICB chief executive and board to ensure the ICB meets the requirements in the DS Act and takes account of this statutory guidance when making commissioning decisions at a system and local level.

ICBs should be open and transparent about who holds these roles and make this information publicly available.

Co-production with people with Down syndrome, their families and carers

NHS commissioners and providers should ensure the inclusion of people with a learning disability, including people with Down syndrome and their families and carers, in developing plans and local decision-making in relation to both learning disability and wider healthcare services. Partnership with people with Down syndrome and their families should start as early as possible.

NHS England has produced further Working in partnership with people and communities: statutory guidance to help providers co-produce plans and service designs. Resources to support co-production can be found in the accompanying 'Annex: resources and examples of good practice'.

Co-production is underpinned by multiple general duties on NHS bodies relevant to engagement and co-production with people and communities, as set out in the National Health Service Act 2006, including a duty for:

- ICBs to promote involvement of patients, and their carers and representatives, in decisions relating to their care or treatment and the prevention or diagnosis of illness in the patient (section 14Z36)
- NHS England and ICBs to involve patients or potential patients, and their carers and representatives, in planning and decision-making in respect of commissioning arrangements of health services (sections 13Q and 14Z45)

Reducing inequalities

Under the National Health Service Act 2006 - specifically sections 13G, 13N, 14Z35 and 14Z42 - NHS England and ICBs have specific duties in relation to reducing inequalities. These duties capture all disabled people, including people with Down syndrome.

NHS England and ICBs must have regard to the need to reduce disparity in access to healthcare and reduce inequalities in outcomes achieved by the provision of health services between people who have a learning disability (which can include Down syndrome) and people who do not. For example, race, religion and learning disability and, in this case, Down syndrome, intersect.

As such, public sector bodies should consider intersectionality and how this is captured in any needs assessments. It is important for staff to understand intersectionality, which should include a learning disability, so that they

understand when commissioning and delivering services how, for example, race, ethnicity and religion may intersect with Down syndrome and lead to further compounded health inequities.
There are tools to help trusts measure the quality of care they provide to people with Down syndrome, including NHS England's Learning disability improvement standards for NHS trusts.

Using data to inform future health service provision

People with Down syndrome may have a specific set of health needs that can change over time, which can have implications for provision and timing of healthcare screening, intervention and treatment. Therefore, it is important that appropriate data collections are in place to capture health and care activity in relation to children, young people and adults with Down syndrome.
Access to high-quality and complete data allows health commissioners, providers and local systems to better understand the needs of the communities they serve and effectively plan future service delivery.
Every ICB must produce an annual report on how it has discharged its functions in the previous financial year. The minimum contents of the annual report are prescribed by the National Health Service Act 2006 (as amended by the Health and Care Act 2022). Section 14Z58 of the National Health Service Act 2006 requires that an annual report must include an explanation as to how an ICB has discharged its legal duties on public involvement and consultation. NHS England has published guidance to help ICBs prepare their annual reports, including how the annual reports should show how intelligence about people's needs and experiences was gathered, and this informed decision-making, governance and quality-checking.
In accordance with section 250 of the Health and Social Care Act 2012, and data information standards DAPB0011: Mental Health Services Data Set and DAPD1069: Community Services Data Set, all providers of NHS-funded mental health and community services should ensure that patient-level data about all NHS-funded activity - including those who are assessed or receive care for a suspected or diagnosed learning disability - are fully and correctly reported to these data sets.
This will include some mental health and community services activity relating to people with Down syndrome. This covers NHS providers and independent providers who are wholly or partially funded by an ICB or by NHS England.
Primary care networks should also ensure their learning disability registers are as up to date as possible, including the identification of people with Down syndrome.
Where learning disability annual health checks are offered by GPs (to people aged 14 and above), the GP maintains a learning disability register. For patients on the learning disability register, annual learning disability health checks and the completion of a health action plan are incentivised in primary care through the Investment and Impact Fund. This also incentivises the recording of ethnicity for the patients on the register.
All organisations and people involved in processing personal data must meet their obligations and responsibilities under the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). Data collected in relation to a person's health, including as relates to Down syndrome, is special category data under the GDPR. Additional safeguards and conditions for processing this data therefore apply. Local authorities, NHS bodies and other organisations must ensure they are aware of, and adequately follow, all legal requirements relating to data protection. The Information Commissioner's Office publishes UK GDPR guidance and resources in relation to GDPR requirements in England.

Delivering health services that meet the needs of people with Down syndrome

There are a range of services and interventions that commissioners and providers are expected to provide for children and adults with Down syndrome, and their families and carers, to protect, improve and support their health. High-quality community-based health services can support primary care to help keep children, young people and adults with Down syndrome well.
To ensure people with Down syndrome have access to the care they need, it is essential that commissioners and providers:

- understand the needs of people in their locality with Down syndrome
- ensure that reasonable adjustments are made to services in accordance with the person's needs

See section '1. Accessible and person-centred services' above for further information on workforce training and making reasonable adjustments for disabled people, which must be considered across all aspects of service provision.

The learning disability improvement standards request all NHS trusts to measure the services they provide to people with a learning disability against a range of different metrics. These metrics are revised annually and developed by people with lived experience, clinical staff and managers. The information gathered is then nationally benchmarked to provide an accurate understanding of both where services are excelling and there are areas for improvement.

Neonatal and postnatal care

Where it has been identified that a parent may be carrying a baby that has Down syndrome, they should be offered appropriate, timely and compassionate care, support and information. Diagnostic testing, investigations and examination, as well as effective discharge planning and postnatal care for the parents and the baby, should be provided and planned in advance, and appropriate services put in place across the ICB, irrespective of where the mother lives and gives birth.

For new parents, the neonatal and postnatal period is an important point to build awareness of the specific and individual needs their child (child, baby or infant) may encounter. All newborn babies (including babies with Down syndrome) must be offered health newborn screening tests, including newborn and infant physical examinations, newborn blood spot screening and newborn hearing screening, in line with national NHS guidance on Newborn screening.

All parents with an antenatal diagnosis of Down syndrome meet the screen-positive criteria for screening examination of the heart and should be managed separately as part of the national screening pathway. Further information can be found in NHS England's Newborn and infant physical examination (NIPE) screening programme handbook. They should be reviewed by a paediatric or neonatal consultant within 24 hours of the NIPE. Babies with postnatally suspected Down syndrome also require review by a paediatric or neonatal consultant within 24 hours of the NIPE. Ongoing referrals will be decided based on examination findings and genetic results.

Where the child has Down syndrome, health visitors should be involved with the child's care until the child goes to school through regular contact with the family.

NHS commissioners and providers should have arrangements in place (with adequate fail-safe mechanisms to ensure outcome of attendance is reported) to offer parents a physical examination of their baby within 72 hours of them giving birth, including where the baby has Down syndrome. This physical examination should, among other screening tests, include a screening test of the baby's eyes. NHS commissioners and providers should have processes in place to refer the baby for more tests should issues be identified. It is important to ensure that necessary mechanisms are in place to ensure onward referrals to specialist health visitor or children's learning disability teams.

NHS commissioners and providers should have arrangements in place to offer parents a newborn hearing test for their baby within the first 3 months (ideally within the first 4 weeks). The newborn hearing screening should be offered to children with Down syndrome unless, for other reasons, they are not eligible. For further information on eligibility criteria, see the Surveillance and audiological referral guidelines.

Arrangements should be in place to refer babies with Down syndrome:

- to hearing specialists should the newborn hearing test not demonstrate a clear response from one or both of the baby's ears
- for targeted follow-up (behavioural testing) at about 8 months of age

Children with Down syndrome should remain under the care of audiology and continue to have their hearing monitored regularly.

Universal support for families

Children's early years are crucial to their development, health and life chances. There is a range of universal support available for families in this period.

The Healthy child programme guidance sets out the local public health, prevention and early intervention activities for all babies, children and young people aged 0 to 19 or up to 25 with SEND, funded through the public health grants to local authorities. These activities are wide ranging and include:

- screening
- immunisation
- health and development reviews
- health improvement
- wellbeing and mental health
- infant feeding

- parenting

Health visiting teams are fundamental to how we support families to give their children the best start in life. They provide support from preconception to age 5. Their contact with parents, carers and children:

- provides vital advice and support
- helps ensure that health, development and safeguarding needs are identified early and the correct interventions are provided

Under regulation 5A of the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013[footnote 4], local authorities must, so far as reasonably practicable, provide or offer the provision of health and development reviews to pregnant women and children (in the local authority area) at 5 specified stages before a child is 30 months old. Where needs are identified (including for children with additional needs due to Down syndrome), the health visiting service will either provide additional support directly or refer to NHS or local services as required.

The joint Department of Health and Social Care (DHSC) and DfE Family Hubs and Start for Life programme is also central to delivering support for babies, children and their families in the community. The programme provides funding to 75 upper-tier local authorities with high levels of deprivation. Family hubs offer support to families with children of all ages (aged up to 19, or 25 for those with SEND), but have a strong focus on the period from pregnancy to age 2. Family hubs can provide a range of support for families including:

- help with infant feeding advice
- parenting classes
- help with the home learning environment
- perinatal mental health support

Building on the Family Hubs and Start for Life programme and in line with the government's Giving every child the best start in life strategy, from April 2026, Best Start Family Hubs will be rolled out in every local authority in England to provide:

- wide-ranging help for families, such as parenting and early development
- strong integration with and co-location of health services

Each Best Start Family Hub will have a child and family service professional specifically trained in working to support parents of children with additional needs. This will help identify children with SEND who may need extra help early on, making links with local early years settings and health services.

General practice

GPs play a crucial role in supporting the health of people with Down syndrome, with fundamental responsibilities in respect of addressing primary healthcare needs, co-ordinating care and supporting people to manage various health conditions.

Everyone with Down syndrome should be identified by their general practice as having Down syndrome and be recorded as such in their clinical record so that they can be identified on their GP learning disability register. Learning disability annual health checks and associated health action plans are an important way to regularly:

- review various health needs someone with Down syndrome may have
- identify any problems or issues as early as possible
- offer them support and advice on how to stay healthy

Everyone with a learning disability, including people with Down syndrome, should be offered an annual health check from the age of 14. GPs should offer an annual health check and health action plan for people with a learning disability under the NHS Network Contract Directed Enhanced Service (DES).

National Institute for Health and Care Excellence (NICE) quality standard [QS187] Learning disability: care and support of people growing older recommends that GPs should offer an annual health check using a standardised template for all people over 14 with a learning disability. GPs should complete and issue a good-quality health action plan to accompany the health check.

To support the health check, GPs must make reasonable adjustments in accordance with the person's individual needs to ensure that the person can get the most out of their annual health check. They should, where necessary, involve a family member, carer, supporter, healthcare professional or social care practitioner who knows the person

well. Gillick competence should be assessed and, where necessary, an appropriate adult must accompany the person when they are under 16.

GPs, health visitors and paediatricians should:

- consider assessment of the presence of health conditions known to be associated with Down syndrome and early intervention - particularly the:
    - monitoring of developmental milestones
    - early identification of delays to development
    - referral to early intervention services where necessary (for example, SLT or occupational therapy)
- consider immunisation and preventative care - including vaccination in accordance with the Complete routine immunisation schedule
- make timely referrals to specialists where a specific need or concern has been identified - including, for example, in relation to cardiology or endocrinology (such as thyroid conditions and onset of diabetes)
- make a baseline assessment for dementia when the person reaches 30
- provide information, health education and support to people with Down syndrome and their families. This includes, among other things, giving advice on how to:
    - manage health conditions
    - understand specific needs
    - recognise signs of ill health
    - navigate the system and where to go for help
- consider signposting to family hubs, which offer support to all babies and children, including those with Down syndrome, bringing services together to:
    - improve access
    - strengthen the connections between families, professionals, services and providers
    - put relationships at the heart of family support

Optometry and eye care

People with Down syndrome are very likely to experience vision issues and are at a higher risk of a range of conditions relating to sight and vision. Compared with the general population, they are 10 times more likely to have a congenital cataract, and infantile glaucoma can also occur (see reference 9). Nystagmus is present in at least 10% of people (see reference 10).

To identify any early problems with their eyes, all babies should receive a routine eye screening within 72 hours of birth as part of the newborn physical examination and again at around 6 weeks of age. The UK National Screening Committee also recommends vision screening in school for children aged 4 to 5 years to look for reduced vision in one or both eyes.

As is the case for everyone, issues with vision can arise later in life among people with Down syndrome. Sight tests are recommended at least every 2 years and more frequently if considered clinically appropriate.

Free NHS sight tests are available for many, including for:

- children under the age of 16, and under the age of 19 in full-time education
- those aged 60 and over
- people on low-income-related benefits
- those diagnosed with diabetes or glaucoma, or considered at risk of glaucoma

Help is also available towards the cost of glasses or contact lenses for children and people on income-related benefits through NHS optical vouchers. Help with optical costs is also available through the NHS Low Income Scheme. We would expect providers of primary eye care services to inform patients of their eligibility to free NHS sight tests and optical vouchers. Further information on help with optical costs is available on the NHS website at Free NHS eye tests and optical vouchers.

To improve access and help address any health inequalities, a free NHS sight test is available to children and young people with SEND attending a special educational setting in England, where the establishment has chosen to host a service.

Commissioners and providers of eye care services must ensure reasonable adjustments are made so that people with a learning disability, including Down syndrome, are able to access services in the same way as other people. This might, for example, include practical adjustments to the environment or changes to the process. The government has published guidance on reasonable adjustments around Eye care and people with learning disabilities. Further guidance on reasonable adjustments can be found in section '1. Accessible and person-centred services' above.

Audiology and hearing

NHS commissioners and providers should ensure that all people with Down syndrome have access to regular hearing tests. GPs should consider referring people with Down syndrome for hearing tests and wider audiology services, where appropriate.

People with Down syndrome are at higher risk of hearing loss or impaired hearing than the general population - research suggests between 51% and 74% of adults with Down syndrome have some degree of hearing impairment depending on the hearing loss criteria used (see reference 11). This can be caused during childhood by 'glue ear' - a fluid build-up in the middle of the ear that affects up to 35% of children with Down syndrome at birth - but there can be other causes too.

The newborn hearing test should identify any impairment to hearing at an early stage. Like vision, however, hearing can become impaired or lost later in childhood and/or adult life.

According to Ears, nose, throat and teeth guidance from the Down's Syndrome Association, a child with Down syndrome should be offered a hearing assessment once or twice a year until the age of 6. A hearing assessment should be offered every 2 years from the age of 6, or more frequently if required. From the age of 35, an annual hearing assessment should be offered.

Free NHS hearing checks are available to all children and young people with SEND in special residential schools at school entry and then at transition points - such as when a child moves from primary to secondary school or secondary school to sixth form college - where the establishment has chosen to host a service.

Speech and language

It is very likely that people with Down syndrome will experience difficulties with speech, language and communication that can impact on relationships, learning and wellbeing. This can include challenges understanding and/or producing speech and/or language. This can be due to multiple factors, including hearing loss.

Where this is the case, people with Down syndrome will require support with communication and language development, and parents will often need help to learn new skills to support the development of their child. People with Down syndrome will often learn differentially to those without - they are often more visual learners, for example.

NHS commissioners and providers may offer people with Down syndrome and their families and carers a range of SLT services and interventions to support their communication, tailored to their specific needs. This should include early intervention services starting from birth, (or diagnosis), to include:

- Establishing early feeding, and supporting the child to develop eating and drinking skills to enable them to eat a full and varied diet. Timely, well supported transition from tube feeding when medically appropriate.
- Advice, training and support for caregivers on supporting and promoting speech, language and communication skills (including parent-mediated intervention)
- Directly provided speech and language therapy sessions developing skills with children and demonstrating strategies with caregivers
- Individualised programmes of intervention tailored to the assessed needs and circumstances of individual children.

This should be available to all families of babies and very babies and very young children with Down syndrome wherever they live, and should include the options of online, in-person groups that families travel to attend, and home visit support, as appropriate to individual circumstances and preferences. Families may access different routes simultaneously or at different times.

This should continue ~~continuing~~ through early years to support a good start in life, and then into primary and secondary school and ~~beyond~~ throughout adulthood.

Local authorities and NHS bodies should work together to commission and provide relevant services to support people with Down syndrome and their families. This could include, for example, local authorities, ICBs and NHS trusts jointly working to embed SLT support in nurseries, schools and colleges. It is important to remember that communication needs are lifelong and do not stop at school age.

SLT services are crucial throughout the lifetime of people with Down syndrome - for example, on admission to hospital, in care settings or if there is concern about dysphagia at any point in their lives. Adequate SLT services, including staff with the relevant skills, must be commissioned by the ICB to meet the needs of their local population. The SLT intervention should be tailored to each person depending on need.

Language outcomes are improved through intervention that:

- is frequent, intensive and sustained over time;
- commences within the first year of life and addresses life-long learning
- delivers direct therapy regularly, complemented by support for language learning at home and in school.
- addresses clear targets set across all language domains addressing the syndrome-specific profile of speech, language and communication needs.

Clearly specified speech and language therapy offered in service pathways for people with Down syndrome across the lifespan recognises the role of syndrome-specific service pathways in securing equitable and effective provision. Services can develop, publish and regularly review Down syndrome pathways from birth and throughout the lifespan

Depending on the person's ability, this could also include enabling access to augmentative and alternative communication (AAC), including the use of technical equipment, such as tablets and apps. AAC comprises a range of techniques that can support or replace spoken communication. ICBs and local authorities should commission local AAC services to support eligible children and adults - which can include people with Down syndrome - who require support with their communication.

NHS England is also responsible for commissioning services for people with the most complex communication needs and should provide specialised AAC services where appropriate. NHS England has published Guidance for commissioning of AAC services and equipment.

Physiotherapy and occupational therapy

Many children and adults with Down syndrome may exhibit low muscle tone, decreased strength and/or delay in acquisition of motor skills in childhood. This can affect mobility and posture and the ability to carry out usual daily activities including using common household equipment in some cases. For example, low muscle tone and ligament laxity associated with Down syndrome can cause reduced muscle strength. Physiotherapy is important for supporting gross and fine motor skills and for building muscular-skeleton strength.

Physical disabilities, as well as a learning disability, can affect the ability of people with Down syndrome to participate in day-to-day activities. Depending on the person, occupational therapy can support them to increase their participation in these activities, including by recommending accommodations or adjustments to activities or environments.

An occupational therapist might also consider how a person's sensory preferences, needs and challenges affect their participation in the daily activities they need and want to do. Where relevant, a sensory assessment will be used to identify appropriate, personalised approaches that support a person's engagement in the environments and activities that are important to them. Collaboration between therapists, caregivers, schools, local authorities and others is essential to create support programmes that meet each person's unique needs.

Physiotherapy may be required beyond childhood and throughout adulthood, but particularly in later life. As the person ages, there is likely to be a need to promote physical activity in relation to weight management and falls, and mobility management is often required. Twenty-four-hour postural care will also be needed if the person develops dementia. Appropriate services should be planned for and commissioned by the ICB.

Many children with Down syndrome will require additional support from allied health professionals - such as SLT, physiotherapy, occupational therapy, podiatry and orthotic, and audiology services - to ensure that they are able to meet their developmental milestones as soon as they can in the best way for them.

These services should be joined up so that families do not need multiple referrals, with a multidisciplinary approach that considers the person and the family needs. Staff should be appropriately skilled to work with people with Down syndrome.

Dentistry

ICBs should consider the specific needs of people with Down syndrome when commissioning primary, secondary and community dental services.

Children with Down syndrome may experience a delayed eruption of their teeth, and both children and adults with Down syndrome may be more susceptible to gum disease than the overall population. Effective oral health is linked to heart health (see reference 12) and therefore good oral hygiene is of paramount importance, as many people with Down syndrome are known to have impaired heart function.

Many people with Down syndrome need extra support or reasonably adjusted information to ensure they are able to understand advice and instruction in relation to oral health. These factors should be considered when commissioning dentistry services. NHS England has published an overall Clinical guide for dentistry in England and Clinical standard: special care dentistry. The government has also published guidance on the provision of Oral care and people with learning disabilities, which may include people with Down syndrome.

To improve access and help address any health inequalities, a free NHS dental check is available to children and young people with SEND in residential special schools and colleges in England, where the establishment has chosen to host a service.

As commissioners of primary, secondary and community dental services, ICBs should ensure processes are in place to plan and manage service provision. As part of this, ICBs should assess local needs, set minimum service standards, and ensure outcome and quality measures are agreed.

Mental health services

Access to community-based mental health and learning disability services

People with Down syndrome may need help with their mental health and wellbeing. Children, young people and adults with Down syndrome should be able to access community-based mental health and learning disability services as required. Under the Equality Act, reasonable adjustments in accordance with a person's needs must be offered to ensure services are as easy to access for a person with Down Syndrome as anyone else.

This guidance does not set out all the mental health services that people with Down syndrome might be able, need or wish to access, but it gives examples of commissioner and provider responsibilities in respect of the range of services.

Further information on the government's plans to reform the Mental Health Act to help ensure people get the support they need in the community, improving care and keeping people out of mental health hospitals, can be found below in the 'Proposed mental health reforms' part of this section.

NHS commissioners and providers should put arrangements in place to ensure that people with Down syndrome who live with severe mental illnesses can access the relevant community mental health services. For people with a learning disability, mental health services should always strive to work in partnership with their local learning disability services. As a result, care can then be tailored to meet their often unique biological, psychological and social needs.

Speech and language therapists are a vital part of the team to support psychologists and psychiatrists in their understanding of, and intervention with, someone with Down syndrome.

Dynamic support registers

ICBs should include people with Down syndrome at risk of admission to a mental health hospital on a dynamic support register. A dynamic support register is a list that helps identify children, young people and adults with a learning disability and autistic people who are at risk of being admitted to mental health inpatient care if they do not receive the appropriate support in the community.

NHS England has issued a Dynamic support register and Care (Education) and Treatment Review policy and guide. This guidance sets out NHS England's expectations for the implementation and use of dynamic support registers in England. Inclusion on the register must be subject to the person's explicit consent or a best interest decision.

Local authorities should also, in carrying out their market function under section 5 (1) of the Care Act, have regard to any information held on the dynamic support register that the ICB has disclosed to them and seek to ensure the needs of people with a learning disability, which can include people with Down syndrome, can be met without detention.

NICE has published guideline [NG11] Challenging behaviour and learning disabilities on support and interventions for people with a learning disability whose behaviour challenges. Professionals and practitioners should take this

guideline into account, alongside the individual needs, preferences and values of their patients or the people using their service.

Inpatient mental healthcare

Wherever possible, we want to see people getting the support they need in the community. However, there may be times when a person with Down syndrome may require treatment for a mental health condition that can only be delivered in hospital. Where hospital treatment is appropriate, this should be therapeutic, for the shortest possible time and the least restrictive possible.

There might be a heightened impact for people with Down syndrome who are in hospital away, or even far away, from their family and friends. It is also important to be aware of considerations when admitting a person with Down syndrome to a mainstream or general mental health ward compared with a learning disability ward.

As for all people in a mental health inpatient setting, it is important to start planning for a person's discharge from hospital - and the community support, care and housing they may need to have put in place - as early as possible and, ideally, at the point of hospital admission. NHS England has published Brick by brick guidance on housing pathways to support hospital discharge for people with a learning disability and autistic people.

Local authorities and NHS commissioners and providers must ensure that staff performing functions under the Mental Health Act follow the requirements set out in the act and have regard to its code of practice, including in relation to people with Down syndrome who have a learning disability.

The code of practice provides statutory guidance to those carrying out specified functions under the act, including:

- registered medical practitioners (including approved clinicians)
- hospital managers and staff (including those of independent hospitals)
- approved mental health professionals

The code also provides statutory guidance to registered medical practitioners and other professions in relation to the medical treatment of patients suffering from mental disorder.

Local authorities and NHS commissioners and providers should understand and take steps to consider less restrictive care options for people with a learning disability, including people with Down syndrome, carefully considering how to preserve the person's rights and freedom of action.

Under section 130D of the Mental Health Act, hospital managers must provide information regarding independent mental health advocates (IMHAs) to certain detained patients and, under the Equality Act, make reasonable adjustments for this to happen - for example, providing a safe place for this meeting without staff present to ensure privacy and confidentiality. To support this, local authorities have a duty to commission sufficient, suitably trained IMHA services for their area.

Everything possible should be done to overcome barriers to effective communication. Hospitals and other organisations should make people with specialist expertise (for example, in BSL or Makaton) available as required.

Where relevant, information about a person's detention (including their rights under the Mental Health Act) must be given to the patient both orally and in writing, including in accessible formats as appropriate and in a language the patient understands. In particular, patients should be given all relevant information, including on:

- complaints
- advocacy
- legal advice
- safeguarding
- the role of CQC

Restrictive interventions in inpatient settings

People with a learning disability, including people with Down syndrome, may at times communicate distress using behaviours that could be perceived to be risky. This may in turn increase the likelihood of staff using restrictive practices in an attempt to reduce or manage risk. People with a learning disability (including those with Down syndrome) are more likely to experience environmental restraint in the form of seclusion or segregation than other groups of people.

The Human Rights Act 1998 (the 'Human Rights Act') sets out the fundamental rights and freedoms that everyone in the UK is entitled to. Public bodies (such as hospitals and mental health services) must uphold these rights. This includes the right to:

- freedom from torture, inhuman and degrading treatment (article 3)

- respect for private life including (but not limited to) autonomy, physical and psychological integrity (article 8)
- non-discrimination (article 14)

There are a number of legal principles and frameworks that any use of restrictive practices must comply with - for example, the Mental Health Act and its code of practice, the MCA (for people 16 or over), and the Mental Health Units (Use of Force Act) 2018.

Disproportionate use of restrictive practices on certain groups of people, such as ethnic minority communities, autistic people and people with a learning disability, must firstly be recognised within services to actively reduce their use on these groups. It is essential that staff teams are supported to make reasonable adjustments in terms of adapted communication, where required, and ensuring people have access to independent advocacy.

Supporting physical health in inpatient settings

As set out in the section 'The health needs of people with Down syndrome' above, people with Down syndrome may need support with a range of co-occurring physical health conditions while they are in receipt of inpatient mental healthcare. Evidence has shown that, when in an inpatient setting for a period of time, people with a learning disability, including people with Down syndrome, have poor physical health outcomes, including increased weight and sedentary behaviour, which are linked to a range of health conditions.

Whenever someone with Down syndrome (or anyone with a learning disability) is admitted to hospital for a mental health condition, their physical health needs should be considered as part of a holistic healthcare plan that is co-produced and supported at all stages, and includes:

- healthy diet
- physical activity (ideally with others)
- management of sedentary behaviour

Where someone's weight is problematic, either over or underweight, a suitable diet should be developed in consultation with a dietitian or nutritionist who understands the additional needs of people with Down syndrome, particularly in relation to constipation management and appropriate fibre and liquid intake.

Care, (Education) and Treatment Reviews

ICBs should organise a Care (Education) and Treatment Review (C(E)TR) to take place when a person with Down syndrome who has a learning disability and/or is autistic is at risk of hospital admission or, if someone is in hospital, to help plan for their ongoing care. NHS England guidance on dynamic support registers and C(E)TRs says that, at the end of a C(E)TR, there should be an agreed action plan that has clear actions, each of which is allocated to a named person with a specific timescale for completion.

Community C(E)TRs aim to help health and social care organisations to identify and put in place additional support that might prevent a person with a learning disability, including people with Down syndrome, being admitted to a mental health inpatient setting. Reviews that take place when the person is in hospital can support good care and timely discharge.

C(E)TRs should involve the person and their family (including carers in the case of children and young people).

Proposed mental health reforms

Through the proposed reforms to the Mental Health Act, the government wants to help ensure that people get the support they need in the community, improving care and keeping people out of mental health hospitals. The reforms specific to people with a learning disability and autistic people are outlined as follows.

Grounds for detention

People with a learning disability and autistic people could only be detained under section 3 of the Mental Health Act if they have a co-occurring mental health condition that requires hospital treatment.

Detention under section 2 would still be possible for a maximum of 28 days for assessment.

The proposed changes would apply to part II only, which applies to civil patients (people admitted to hospital from the community), rather than those within the criminal justice system (covered in part III of the act).

Establishment of dynamic support registers

As set out in new section 125D of the Mental Health Act, ICBs would be under a duty to establish and maintain dynamic support registers of those who have risk factors for detention under part II of the act.

This is to improve monitoring of the needs of - and support for - people who may be at risk of experiencing a mental health crisis and being detained under the act.

Role of dynamic support registers in commissioning

New section 125E of the Mental Health Act provides that ICBs, when carrying out their commissioning functions, must:

- have regard to dynamic support registers and the needs of their 'at risk' population
- seek to ensure that the needs of people with a learning disability and autistic people can be met without detaining them under part II of the act

Section 125E also provides that local authorities, when carrying out their market functions[footnote 5], must:

- have regard to any information disclosed to them by virtue of the dynamic support register
- seek to ensure the needs of people with a learning disability and autistic people can be met without detaining them under part II of the act

Adherence to C(E)TRs

Responsible commissioners would be required to make arrangements to ensure that a C(E)TR is held following a patient's admission to hospital.

Certain bodies would be required to have regard to its recommendations, meaning they are followed unless there is a good reason not to do so.

Provision of community support

The proposed changes to the detention criteria in part II of the Mental Health Act would only commence when there are strong community support provisions in place.

Transition from children's to adults' services

It is important to ensure a smooth transition period when a young person moves from children's to adults' services. Professionals from education, social care and health services should work with the young person with Down syndrome and their family and/or carers to develop a transition plan as early as possible.

Section 16 of the Care and support statutory guidance sets out local authorities' responsibilities and duties relating to the transition from children's to adults' social care services under the Care Act.

NICE has set out quality standard [QS140] on Transitions from children's to adults' services, which covers all young people (aged up to 25) using children's health and social care services who are due to make the transition to adults' services. This includes:

- young people with:
    - mental health problems
    - disabilities
    - long-term, life-limiting or complex needs
    - rare diseases
- those in secure settings or under the care of local authorities

According to the SEND code of practice, which covers people with Down syndrome aged 0 to 25 years, a transition plan should be co-produced with the young person and, where appropriate, their family that identifies who will take the lead in co-ordinating care and referrals to other services. The young person should know who is taking the lead and how to contact them.

NHS bodies, alongside local authorities, should:

- keep provision under review so any gaps in support between children's and adults' services can be identified and addressed
- ensure there are arrangements in place to support young people with complex care needs - including people with Down syndrome - who are making the transition from children's to adults' services
- put systems in place so that referrals can be made directly from any children's service to the equivalent and relevant adults' service without the need for a re-referral from, for example, GPs or consultants

Local authorities must also consider the transition to adulthood for young people who are vulnerable, disabled or need additional support, including the:

- interface with services for young people aged 16 to 25. For example, school nursing teams should work with adults' services to ensure a smooth transition, including to adults' mental health services

- transition of safeguarding support from children's to adults' services, which is vital to ensure that people with Down syndrome who are experiencing abuse or neglect are fully supported

In June 2021, the Chief Social Worker's office worked with the sector to develop a knowledge briefing entitled Bridging the gap: transitional safeguarding and the role of social work with adults. This publication focuses on what transitional safeguarding is, and how good-quality adult social work can ensure that children who are transitioning into adulthood are protected from harm.

Identifying and responding to increased risk of dementia for people with Down syndrome

Dementia, including Alzheimer's disease, affects adults with Down syndrome more frequently and at a younger age than the general population - the average age of diagnosis being 55 years old. Some research estimates that the lifetime risk of people with Down syndrome developing dementia is more than 90%.

For these reasons, the NHS advises that people with Down syndrome have regular check-ups from the age of 30 to look for signs of dementia. Advice on health conditions associated with Down syndrome, including Alzheimer's disease and dementia, can be found on the NHS website. NICE guideline [NG54] Mental health problems in people with learning disabilities: prevention, assessment and management also advises that a special focus on dementia is required for people with Down syndrome. It is also important to ensure that physical illnesses do not go undiagnosed due to diagnostic overshadowing.

The NICE guidelines recommend that:

- during annual health checks, as appropriate, clinicians ask the person with Down syndrome and their family members, carers or care workers (as appropriate) about family history and any changes that might suggest the need for an assessment of dementia, such as:
    - any change in the person's behaviour
    - any loss of skills (including self-care)
    - a need for more prompting in the past few months
- clinicians consider supplementing an assessment of dementia for an adult with a learning disability with measures of symptoms, such as the:
    - Dementia Scale for Down Syndrome (DSDS)
    - Dementia Questionnaire for People with Learning Disabilities (DLD)
    - Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)
- GPs, or others caring for adults with Down syndrome, should complete a baseline assessment of 'adaptive behaviour' (the person's daily living skills)

The genetic and physiological differences of people with Down syndrome also have some impact on the effectiveness of treatment for dementia. NICE guidelines recommend a tailored, evidence-based approach to medication that considers the individual circumstances and factors such as patient preferences and specific health needs.

Palliative and end-of-life care

Commissioners and providers of health and social care should make sure that people with Down syndrome have equal access to high-quality, personalised palliative and end-of-life care. NICE guideline [NG96] Care and support for people growing older with learning disabilities includes a section on end-of-life care.

The life expectancy of people with Down syndrome has significantly improved in the past few decades. The average life expectancy of a person with Down syndrome is now around 60 years (see reference 4) and has increased substantially in recent years - as recently as 1983, a person with Down syndrome lived to be only 25 years old on average (see reference 13).

As is the case for anyone with palliative or end-of-life care needs, people with Down syndrome will have a range of needs that they may need support with - ranging from health needs such as symptom management through to emotional and spiritual needs. People with Down syndrome may also face additional or particular challenges. This may include:

- being less able to understand information about their treatment options
- being less able to communicate their concerns, wishes or preferences
- experiencing more complicated physical or mental health problems

- having more difficulty accessing services

A range of other bodies have also published guidance on end-of-life and palliative care. NHS England, for example, issued guidance on Delivering high quality end of life care for people who have a learning disability, which provides resources and guidance for commissioners, providers, and health and social care staff. ICBs and NHS bodies should consider this guidance when planning end of life care services.

The NHS is clear that it is unacceptable that people have a do not attempt cardiopulmonary resuscitation (DNACPR) decision on their record simply because they have a learning disability. This is set out in NHS England's published letter on DNACPR and people with a learning disability and or autism. The terms 'Down syndrome' and 'learning disability' should never be:

- a reason for DNACPR decision making
- used to describe the underlying, or only, cause of death

A learning disability itself is not a fatal condition: death may occur as a consequence of co-occurring physical disorders and serious health events.

Every person has individual needs and preferences that must be taken account of, and everyone should always receive a good standard and quality of care. Discussions regarding cardiopulmonary resuscitation preferences should take place as part of a wider conversation regarding a person's preferences, wishes and needs related to their future care. Reasonable adjustments in accordance with a person's individual needs should be provided to allow people to have that conversation.

Workforce education and training

Staff may need education and training to support them to deliver services to people with Down syndrome. In this case, raising awareness and understanding of the diverse needs of people with Down syndrome is very important to effective services and support. Training for professionals working within health, social care, housing, education settings and beyond is important to help build this knowledge base and inform plans to support these needs.

Equality and diversity training

All bodies, including public sector bodies, discharging a function of a public body should ensure that their staff receive robust equality, diversity and inclusion training to best meet their public sector equality duty (which is found in the Equality Act). This includes any organisation delivering services under, for example, an NHS standard contract. It is crucial that professionals working with people with Down syndrome receive the necessary training to help reduce discrimination, ensure fair treatment and build understanding of the diverse needs associated with Down syndrome.

There are several sources of good practice that public bodies could consider when choosing the equality, diversity and inclusion training to be received by their staff. NHS Employers, for example, has published Equality, diversity and inclusion training: a good practice guide, which sets out a framework for how NHS organisations can deliver such training.

Public bodies should also consider the intersectionality of other protected characteristics for people with Down syndrome. For example, a person with Down syndrome may be from an ethnic minority community or may identify as LGBTQ. Staff should be trained to understand the impact of the different protected characteristics that people may have as well as their Down syndrome diagnosis.

Health and social care workforce

It is essential that health and care staff working with adults and children with Down syndrome have the right skills, knowledge and training to enable them to provide high-quality care and support.

All health and adult social care services that are registered with the Care Quality Commission (CQC) must ensure that their staff receive such appropriate support, training and professional development as is necessary to enable them to carry out the duties they are employed to perform - as required by regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

Under the Health and Social Care Act 2008 (as amended by the Health and Care Act 2022), CQC-registered health and social care providers must ensure staff receive training on learning disability and autism appropriate to their role. The Oliver McGowan Mandatory Training on Learning Disability and Autism is the government's recommended training package to meet this requirement. Some staff who work frequently with people with Down syndrome may require additional training on Down syndrome.

The Oliver McGowan code of practice guides providers on how to meet the statutory training requirement. It was published and laid in Parliament on 19 June 2025, and became final on 6 September 2025. The code sets expectations on learning disability and autism training content and delivery, ensuring that health and care staff are sufficiently trained to effectively work with people who have a learning disability and autistic people, including when they may also have Down syndrome.

Professionals working outside of CQC-regulated services would also benefit from such training. This will help build the awareness, understanding and skills required to effectively care or deliver services for people with Down syndrome, who often have a learning disability and may have a co-occurring diagnosis of autism. Local authorities and NHS bodies may also wish to refer to the Statutory guidance to support implementation of the adult autism strategy, published under the Autism Act 2009, for further detail on supporting autistic people.

In designing local training offers for staff, commissioners and providers should co-produce this training with people with a learning disability and their families and carers, including people with Down syndrome. This includes co-production of training materials and/or planning for the provision or delivery of training. This could include working with people with Down syndrome to understand how training might be tailored to build awareness and understanding around specific needs. The 'Involving people with lived experience guidance' PDF on the NHS England workforce, training and education resources page describes how to involve people with a learning disability and autism in designing and developing local training offers.

Commissioners and providers of health and care services should have regard to the Oliver McGowan code of practice when designing and delivering their local training offers. CQC will take into account the code when assessing whether or not registered providers are meeting the legal requirement. All registered providers will need to ensure that staff receive training appropriate to their role to comply with the law and must be prepared to demonstrate to CQC how their chosen approach meets the code.

Down syndrome warrants recognition as a defined area of specialist practice within speech and language therapy. All SLT staff working with individuals who have Down syndrome requires a sound understanding of syndrome-specific approaches and their underlying rationale. Aspects of syndrome specific intervention that may be overlooked in contemporary clinical practice with people who have learning disabilities are outlined in A Guidance Pack for speech and language therapists from the Royal College of Speech and Language Therapists' Clinical Excellence Network focused on Down syndrome: see Key information for speech and language therapists: addressing speech, language and communication needs in Down syndrome.

Speech and language therapy provision in statutory services for clients with Down syndrome may be overseen by speech and language therapists with specialist knowledge and skills in working with this client group.

Specialist speech and language therapists play a vital role in ensuring effective provision that realises potential for clients with Down syndrome.

They may be responsible for developing services that meet the needs of this client group, including designing and implementing care pathways.

Specialists also guide and support other speech and language therapy staff, ensuring that all team members are familiar with the syndrome-specific profile and interventions.

Additionally, specialists assess and advise on speech and language therapy needs, and design and deliver intervention for clients who require more expert management.

These therapists must possess comprehensive and up-to-date specialist knowledge, including an in-depth understanding of syndrome-specific interventions, assessment issues, and critical appraisal of relevant research.

Training needs across the speech and language therapy workforce should include:

- Knowledge of syndrome specific issues and approaches for all staff working with clients with DS, which may be commissioned for local teams or accessed as individuals, and is likely to involve 4-6 hours Continuing Professional Development (CPD)
- Leads for DS (in local NHS SALT services or within specialist schools or colleges): these therapists require more in-depth higher level training which can be accessed through self study, online training or live training, and is likely to exceed 2 days training/study.
- Access to tertiary level support and expert guidance may be available through specialist services where expert speech and language therapists in advanced practitioner roles can advise and support local services.

- Speech and language therapy staff in specialist services such as AAC hubs or services for eating drinking and swallowing difficulties who work with people with Down syndrome should have in-depth knowledge of Down syndrome for their area of specialism.

Workforce requirements within educational settings

Educational support tailored to individual needs and settings is essential for maximum academic progress and social inclusion for children and young people with Down syndrome. Practitioners working in education settings should understand the needs of the pupils they educate and, where they have pupils with Down syndrome, this includes an awareness and understanding of the learning profile associated with Down syndrome.

'Annex: resources and examples of good practice' includes resources produced by third-sector organisations that can help teachers to extend their knowledge on how to support children and young people with Down syndrome.

There are many qualifications and training requirements for the education workforce, including national plans to train teachers who support learners with SEND. Qualification requirements for those working in early years settings are outlined in the Early years foundation stage statutory framework, which is given power through the Early Years Foundation Stage (Welfare Requirements) Regulations 2012. To meet the requirements to work in staff-to-child ratios as qualified members of staff, staff must have an approved ('full and relevant') qualification that is recognised by the Department for Education (DfE) as meeting its criteria. Approved qualifications are set out on the Early years qualifications list.

For professionals working in schools, initial teacher training (ITT) is underpinned by the Education (School Teachers' Qualifications) (England) Regulations 2003. This includes the requirements for trainees to obtain qualified teacher status (QTS) after an end-point assessment against the teachers' standards. For ITT courses that lead to QTS, ITT providers accredited by DfE under the ITT criteria must incorporate the ITT core content framework (CCF) in full as a basis for their course curricula.

Teacher induction after obtaining QTS is underpinned by the Education (Induction Arrangements for School Teachers) (England) Regulations 2012. During induction, early career teachers complete training based on the Early career framework (ECF). Both the CCF and ECF include a section on adaptive teaching that references the SEND code of practice: 0 to 25 years and the need for teachers to work with the SEND co-ordinator and other professionals, and support SEND pupils. All teachers must meet the teachers' standards, which set the minimum requirements for teachers' practice and conduct. These standards set clear expectations that teachers must understand the needs of all pupils, including those with SEND. From September 2025, the CCF and ECF are being replaced by a combined and updated Initial teacher training and early career framework, which contains more content related to adaptive teaching and SEND.

There is no legal or regulatory requirement for those teaching in the further education (FE) sector to hold a specific teaching qualification or professional status - this is at the discretion of individual employers. In practice, most sector employers consider FE teachers to be fully qualified if they hold a relevant teaching qualification at level 5 or above - such as a Diploma in Teaching (Further Education and Skills) or a Postgraduate Certificate in Education (PGCE) - or have completed a Learning and Skills Teacher apprenticeship at level 5.

From September 2024, all courses for FE teacher training that attract public funding must be based on the occupational standard for learning and skills teachers. The occupational standard sets out the skills, knowledge and behaviours that effective FE teachers require, and includes a core duty to:

work in a manner that values diversity, and actively promote equality of opportunity and inclusion by responding to the needs of all students.