



Down Syndrome CEN: working
to support children and adults
who have Down syndrome.

DS CEN Position Paper on the Government's Draft Statutory Guidance, Annex, and Needs Profile Paper (DS Act 2022)

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.

DS CEN Response

There is much to commend in the draft Guidance, the Annex, and the Needs Profile.

We welcome the emphasis on accessible information and on ensuring equitable access to services and life opportunities.

However, **the guidance is insufficiently robust in relation to speech and language therapy provision.**

While it acknowledges a syndrome-specific profile of speech, language and communication needs, **it does not adequately describe established good practice in speech and language therapy provision for people with Down syndrome.**

The need for a stronger emphasis on speech, language and communication needs is essential due to **the right to communication being enshrined in the Human Rights Act**, and difficulty with communication restricting every area of life, and potentially causing significant behaviour challenges if not sufficiently supported.

There is a risk that variability in understanding and implementation will persist.

We share below recommendations for amendments and additions that can address this.

1. Addressing Speech and language and communication needs
2. Service Pathways
3. Workforce training
4. Early Intervention
5. Feeding

Recommendations: Guidance on addressing speech, language and communication needs

In describing speech, language and communication, the paper states:

“Detailed guidance on how you might support those needs is not within this paper’s scope, but may be referenced in supporting evidence where this was provided during the call for evidence exercise.”

However, this appears inconsistent with other sections of the Needs Profile paper, where specific strategies and practice implications are explicitly referenced.

For example:

- **Immune function**– The paper highlights the importance of vaccination and access to acute and emergency healthcare.
- **Education settings, social inclusion and participation**– It references evidence suggesting improved spoken language, reading outcomes and academic progress in fully inclusive classrooms.
- **Higher education and employment**– It states that barriers to inclusion in further education need to be removed to support successful transition to adulthood and employment.

These sections go beyond describing needs and make practice-related statements about what improves outcomes.

In contrast, the section on speech, language and communication does not set out equivalent evidence-informed principles regarding effective intervention. This fails to advance the critical role of direct speech and language therapy.

The Needs Profile paper (speech and language section) should state explicitly that:

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.**

This evidence-based statement captures information from the RCSLT’s publication setting out evidence-based speech and language therapy for people with Down syndrome (Burgoyne 2020), which is omitted from the *Annex: resources and examples of good practice*:-

Clinical Excellence Network (DS CEN) is currently referenced under the heading *Effective Communication and Sharing in the Annex*

This document describes speech and language therapy intervention rather than effective sharing of information with people with Down syndrome. It appears to have been placed in this section in error.

This guidance would sit appropriately alongside the *Down Syndrome Toolkit for Paediatric Speech and Language Therapists* within the *Speech and Language* section of the Annex, rather than in its current location.

In addition, a second key document — the only syndrome-specific guidance published by the Royal College of Speech and Language Therapists — should also be referenced in the *speech and language* section. The *Ask the Expert* article- ***Down’s syndrome: language development and intervention*** published in the RCSLT’s Bulletin August 2020



www.rcslt.org/wp-content/uploads/2022/04/Ask-the-Experts-Downs-syndrome-bulletin-august-2020.pdf provides clear guidance on the principles underpinning effective intervention, set out above

Without explicit reference to this professional guidance published by the Royal College of Speech and Language Therapists, **the document fails to specify what constitutes high-quality speech and language therapy provision.**

Access to speech and language therapy in adulthood is insufficiently addressed.

In the Speech and Language section, it is stated that *SLT services and interventions may be offered from birth, continuing through early years to support a good start in life, and then into primary and secondary school and beyond.* These services are offered **throughout adulthood.**

(addition to Access to community-based mental health and learning disability services)

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.

Recommendation: Training speech and language therapy staff

The draft guidance states:

“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.”

Evidence provided by the Royal College of Speech and Language Therapists discusses this in terms of specialism:-

It is essential ... that everyone who has a genetic condition has access to speech and language therapy services at the appropriate level of specialism to identify and meet their communication and swallowing needs. Down Syndrome Act 2022 guidance: call for evidence – response from the Royal College of Speech and Language Therapists (RCSLT)

The guidance can set out a training framework for speech and language therapists aligned the practise of specialisms within statutory speech and language therapy, to ensure delivery of speech and language therapy that meets the needs outlined above. Through Continuing Professional Development (CPD) therapists develop specialist (Band 6) skills, building comprehensive knowledge of assessment, management and intervention for specific client groups, settings and diagnoses.

Individuals with Down syndrome receive speech and language therapy in a range of settings: early intervention services for disabled children, community clinics, mainstream school services, special school provision, further education colleges and adult learning disability services, mental health services, older adults services, and may receive service within specialist pathways including eating and drinking difficulties, speech sound disorder, voice output communication devices/speech generating devices.



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This can lead to piecemeal access to syndrome-specific expertise. As a consequence, specialist knowledge about the distinctive communication profile associated with Down syndrome and how to address this has not always been systematically embedded within local services.

When speech and language therapists hold clinical responsibility for individuals with Down syndrome, specialist knowledge of learning disability, eating, drinking and swallowing difficulties, and practice within settings such as mainstream schools, or community teams for adults with learning disabilities, should be complemented by syndrome-specific expertise.

Down syndrome warrants recognition as a defined area of specialist practice within speech and language therapy. (addition to health and social care workforce section- see below)

Syndrome-specific expertise has developed through innovation within statutory services, and through initiatives of parent-led support groups, securing access to syndrome specific speech and language therapy.

Highly specialist therapists, often in clinical lead roles, provide leadership and clinical support to specialist therapists in areas such as speech sound disorders, fluency and autism. In some services there are clinical leads for Down syndrome- this model can be adopted to support speech and language therapy staff in meeting the needs of clients with Down syndrome.

Expert specialist therapists (in emerging advanced practitioner or consultant roles) provide expert guidance through tertiary centres cascading guidance to local teams. This may currently be accessed through third sector organisations. Specialisms in Down syndrome should be strengthened in regional AAC hubs and tertiary centres.

Many statutory services have ensured workforce development through training that ensures that practitioners at all levels are equipped with the knowledge and skills required to deliver high-quality, evidence-informed support to individuals with Down syndrome across the lifespan: with the right skills, knowledge and training to enable them to provide high-quality care and support.

(addition to health and social care workforce section)

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.



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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.

This follows models in other areas of speech and language therapy set out above e.g. neuromotor based speech sound difficulties; or stammering- responsible practitioner must understand the condition and interventions.

- Local specialist in SSD /dysfluency supports the practitioner.
- Expert centres provide advice and guidance e.g. specialist combined ENT/oral difficulties clinic, or Michael Palin Centre.

Recommendation: Service Pathways

Service pathways set out clearly what speech and language therapy individuals with Down syndrome, and their families and support networks, can expect to access. They describe how and when speech and language therapy will be provided, and how services will respond at key points in development and transition. Speech and language therapy services routinely establish pathways for particular areas of need, presenting issues and settings; the same structured approach should apply to Down syndrome.

Specific care pathways help ensure appropriate and timely responses from services, reduce variability in provision, and improve outcomes for people with Down syndrome and their families.

Evidence submitted by the Royal College of Speech and Language Therapists in response to the Down Syndrome Act 2022 guidance highlights the effectiveness of specific care pathways.

Clear pathways support timely intervention, coordinated working and consistent standards of care.

There is also a good understanding amongst other staff in specialist learning disability teams/services, especially where there are specific care pathways in place, of how to support the specific needs of people with Down's syndrome. However, across wider acute and community services there are often gaps in this understanding. This is particularly the case among professionals who are less likely to come into contact with people with learning disabilities or Down's syndrome. This indicates a training and knowledge gap. Down



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Some services have already developed and shared Down syndrome–specific pathways, that may focus on particular ages or life stages. These provide useful models of good practice.

(addition to speech and language section)

The guidance should explicitly recognise the importance of: clearly specified speech and language therapy offered in service pathways for people with Down syndrome across the lifespan, that 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

Recommendation: Early Intervention

The Needs Profile paper identifies “early and targeted intervention” as a key theme. However, it does not define what this means in practice, nor does it reference the evidence base underpinning effective early intervention for children with Down syndrome.

Without clarification, the term risks becoming aspirational rather than operational.

We recommend expanding with additional info as in bold below (speech and language section)

Access to specialist support from speech and language therapy 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.

Feeding

The section on feeding, diet, weight gain and growth within the Needs Profile paper does not reference the well-established feeding difficulties associated with Down syndrome. This omission is notable, particularly given that the paper does mention food refusal behaviours associated with Williams syndrome when describing conditions with overlapping needs.

Feeding difficulties in individuals with Down syndrome are widely documented and may include oral–motor challenges, delayed development of chewing skills, sensory sensitivities and refusal of certain textures or accepting only a narrow range of foods, and increased risk of dysphagia.

The absence of reference to speech and language therapy involvement in feeding difficulties specific to Down syndrome does not recognise current common practises and the essential role of speech and language therapists with feeding difficulties.

Including reference to this would ensure parity with other conditions referenced in the document and would provide a more accurate and complete representation of need. It would also reduce risks and stress resulting from feeding difficulties.



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The Down Syndrome Clinical Excellence Network (DS CEN) *Key Information for Speech and Language Therapists* sets out relevant references describing these feeding and swallowing differences and their clinical implications.

“There is a high prevalence of dysphagia and risk of aspiration in young children with DS and feeding issues throughout life (Cooper-Brown et al., 2008; Hennequin et al., 2000). Screening for feeding and swallowing concerns is recommended for all babies with DS (Stanley et al., 2019) with ongoing monitoring of effects (RCSLT, 2024). In childhood, feeding evaluation should target overcoming activity limitations and participation restrictions, to improve overall quality of life (Anil et al., 2019). Syndrome specific protocols should support eating and drinking skills throughout childhood (Anil et al., 2019) including promoting developmental progression, and managing sensory and behavioural needs.”

This information should be included in the Needs Profile Paper

It is also extremely important people with Down’s syndrome have access to speech and language therapy so their eating, drinking and swallowing are fully assessed. Services must also know when to refer to speech and language therapy to ensure dysphagia is identified and managed appropriately Down Syndrome Act 2022 guidance: call for evidence – response from the Royal College of Speech and Language Therapists (RCSLT)

(addition to The health needs of people with Down syndrome section)

Feeding difficulties requiring management by speech and language therapy, often working as part of specialist feeding teams, must be available

- 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
- managing eating and drinking difficulties throughout the lifespan, including loss of skills associated with aging and/or dementia.

Children/adults with Down syndrome have significantly increased airway safety risks. These risks include aspiration, obstruction, respiratory infections, and impaired airway clearance. Which can cause; Recurrent chest infections; Increased hospital admissions; Long-term lung damage; Reduced quality of life; Premature death. The SLTs role is to identify these risks and minimise them.