



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

Down Syndrome Act 2022 draft statutory guidance: DS CEN's summary of key points in response to the consultation

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.

The Key Points

Below is the key information covered in the DS CEN's position paper 2026 which we recommend is included in the draft guidance Section 2: High-quality and holistic healthcare, The health needs of people with Down syndrome 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>

Section/page number	Add
Accessible and Person Centred Services - Health and Social Care workforce	<p>Down syndrome warrants recognition as a defined area of specialist practice within speech and language therapy.</p> <p>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.</p> <p>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.</p> <p>Specialist speech and language therapists play a vital role in ensuring effective provision that realises potential for clients with Down syndrome.</p> <p>They may be responsible for developing services that meet the needs of this client group, including designing and implementing care pathways.</p> <p>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.</p>

	<p>Additionally, specialists assess and advise on speech and language therapy needs, and design and deliver intervention for clients who require more expert management.</p> <p>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.</p> <p>Training needs across the speech and language therapy workforce should include:</p> <ul style="list-style-type: none"> ▶ 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.
<p>High Quality and Holistic Healthcare – The Health needs of people with Down syndrome</p>	<p>Feeding - Feeding difficulties requiring management by speech and language therapy, often working as part of specialist feeding teams, must be available to establish infant feeding, manage transition from tube feeding, support the development of a range of eating and drinking skills to ensure access to a full and varied diet, and manage eating and drinking difficulties throughout the lifespan, including loss of skills associated with aging and/or dementia.</p> <p>The diet, weight gain and growth should then be a separate point with the current text in the draft guidance.</p>
<p>High Quality and Holistic Healthcare - Designing and Planning Health Services</p>	<p>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.</p> <p>Services can develop, publish and regularly review Down syndrome pathways from birth and throughout the lifespan. These could be overseen by the Executive lead for Down syndrome on the ICB.</p>
<p>High Quality and Holistic Healthcare Speech and Language therapy</p>	<p>Aspects of syndrome specific intervention that may be overlooked in contemporary clinical practice with people who have learning disabilities are outlined in “Key information for speech and language therapists: addressing speech, language and communication needs</p>

	<p>in Down syndrome from the Royal College of Speech and Language Therapists' Clinical Excellence Network focused on Down syndrome. DS CEN Guidance Down Syndrome CEN</p>
<p>High Quality and Holistic Healthcare Speech and Language therapy</p>	<p>Language outcomes are improved through speech and language therapy intervention that:</p> <ul style="list-style-type: none"> • 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. (Burgoyne, 2020) www.rcslt.org/wp-content/uploads/2022/04/Ask-the-Experts-Downs-syndrome-bulletin-august-2020.pdf
<p>High Quality and Holistic Healthcare Speech and Language therapy</p>	<p>This should include early intervention services starting from birth, (or diagnosis), to include:</p> <ul style="list-style-type: none"> ▶ 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. <p>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.</p> <p>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.</p>
<p>Access to community-based mental health and learning disability services</p>	<p>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.</p>