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

Key information for SaLTs: Addressing SLCN in DS

High quality evidence-based speech and language therapy intervention addressing speech skills AND language skills AND communication skills should **commence during the first year of life** and be sustained into adolescence and adulthood, given evidence of continuing gains (Burgoyne, 2020) and "the importance of communication in enabling … full potential in society" (Murphy et al., 2017).

We first consider the syndrome specific profile and then we look at key domains in more detail, across the life span.

Syndrome specific profile:

1. DS is associated with a distinct speech and language profile that does not mirror cognitive development.

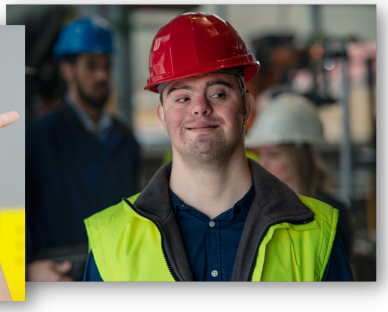
Speech and language skills are areas of relative weakness compared to non-verbal IQ. "DS is associated with a distinct language profile characterised by relative strengths in receptive vocabulary and significant impairments in auditory processing, expressive language, phonology and grammatical skills (e.g., Næss et al., 2011). Pragmatic communication skills are typically stronger than linguistic skills, but there are pragmatic difficulties nonetheless (Smith et al., 2017)", (Burgoyne, 2020).

2. Assessment and intervention must take account of the DS specific profile and the wide range of individual needs, including when autism is suspected.

Speech and language therapy goals should target speech, vocabulary, grammar, and functional communication through specific interventions, and address real life communication challenges (Rondal & Buckley, 2003). It is of utmost importance with this client group to establish a strong relationship with the client, and to work with their interests and motivations. Access to speech and language therapy should not be withdrawn or denied due to behaviour issues.

3. The amount of intervention matters.

"Children with DS who receive more frequent intervention make greater gains in learning (Burgoyne, 2012; Yoder et al., 2014). It is vital that speech & language therapists (SaLTs) deliver direct therapy regularly" (Burgoyne, 2020). They should also train parents and educators in teaching activities and syndrome specific learning needs, so that they can provide daily support for language learning (Burgoyne, 2020).



4. Hearing should be closely monitored and optimised.

Fluctuating hearing loss and history of hearing loss account for variation between individuals' speech and language development (Laws & Hall, 2014). SaLTs should ascertain hearing status, and take this into account when assessing and delivering intervention. SaLTs should also include support for hearing when advising on strategies to support communication.

5. Speech and language therapy is relevant throughout adulthood.

As people with DS move through life, they may benefit from SaLT support to access employment, navigate relationships, self-advocate and to manage any mental health issues and later life challenges including decline in skills and onset of dementia.

6. Individuals are best engaged and motivated through their interests and responsive strategies.

Therapy and assessment must be responsive and flexible in order to accommodate the specific attention shifts and motivational challenges of people with DS. (Miller et al., 1999). Learners with DS are particularly sensitive to failure, if they find a task too difficult or perceive it to be so, this may result in apparent poor attention to task and avoidant behaviour. Errorless learning is therefore important for this population.

7. Speech and language therapists play a vital role in addressing challenging behaviour and enhancing quality of life through support for positive behaviour.

SaLTs bring expertise in identifying messages communicated through behaviours, and advising on effective strategies to communicate unmet needs, in order to decrease behaviour issues (Feeley & Jones, 2006; Stein, 2016).

8. Respectful descriptors are valued by the DS community.

Person first language is usually preferred (e.g., people with DS). Terms such as "more complex, difference, or condition" are more acceptable than "low functioning, abnormality, or disorder" respectively. If in doubt, ask.

If you are a SaLT working with the Down syndrome community join the DS CEN to access further information, presentations, research, and peer support **here**.

For an introduction to this guidance click here

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Key domains across the lifespan:

9. 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.

10. Targeted vocabulary teaching with visual supports utilises areas of strength to improve communication.

Vocabulary is an area of strength relative to syntactic skills. Receptive vocabulary targets should build on strength in comprehension, with separate targets for expressive vocabulary, as vocabulary output does not keep pace with comprehension. Vocabulary teaching should build on world knowledge and should systematically teach concepts for the individuals' key stage/age group.

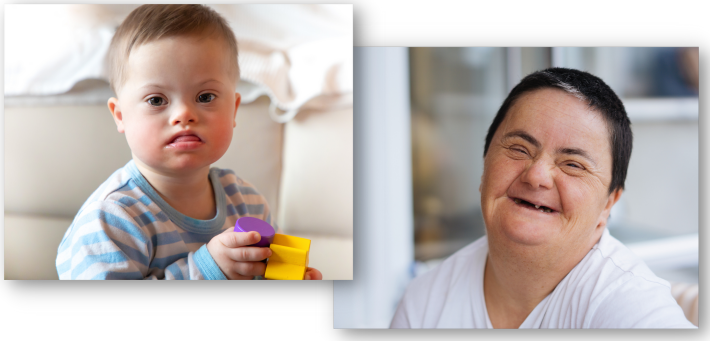
11. Language impairments can be addressed using strengths in visual processing to compensate for weaknesses in auditory processing.

Individuals with DS have difficulty maintaining and storing phonological patterns of words (Jarrold et al., 2009) and grammatical structures (Rondal, 2017). Numerous studies have demonstrated gains when visual supports are used to teach: vocabulary e.g., written words, objects, signs, pictures/symbols (Burgoyne et al., 2012); syntax e.g., shape coding, (Tobin & Ebbels, 2018); morphosyntax e.g., written word (Baxter et al., 2021); and narrative skills e.g., story maps (Westerveld & van Bysterveldt, 2022). Teaching whole word recognition to rehearse language through reading has been advocated since the 1970s, and researchers discuss the use of strengths in visual processing as 'well justified' (Fidler, 2005).

12. While early strengths in social interaction are apparent, use of language for more complex pragmatic functions may require support.

Young children with DS show strengths in social interaction e.g., sharing and cooperation (Sigman & Ruskin, 1999) and non-verbal communication (Fidler, 2005; Franco & Wishart, 1995; Smith et al., 2017).

Later more complex pragmatic skills that rely on language are more delayed (e.g., Laws & Bishop, 2004; Smith et al., 2017). Strong social sensitivity and aspiration "to be treated like everybody else" (Jessop, 2023) demands intervention that enables use of age appropriate language and expresses personality.



13. Speech intervention is not contingent on expressive language levels and should begin early, addressing the syndrome-specific speech disorder.

Intervention can address the known syndrome-specific speech disorder and should start in the first year of life (Miller et al., 1999). Research points to underlying deficits in:- phonological awareness; prosody; oral structure; motor speech skills; and apraxia of speech. These impact on speech intelligibility as well as phonological development (Kent & Vorperian, 2013; Rupela et al., 2016; Wong et al., 2015). Therefore, comprehensive assessment is essential to identify specific deficits and devise individual programmes of intervention, with the overall aim of enhancing speech intelligibility. A range of approaches have been used effectively: notably, Van Bysterveldt et al., (2009) highlight use of visual representations of speech sounds.

14. Disruptions to fluency and prosody are common features of speech in DS and should be considered in assessment.

Management of fluency issues should be informed by a thorough and holistic assessment of communication, including speech, language and social interaction skills, and environmental factors. SaLTs should work with communication partners to implement strategies that make communication easier and promote fluency. Direct work on speech, language and communication skills can build capacity for fluency. Fluency control strategies should be considered particularly if a client is reacting to the dysfluency e.g., avoids speaking, or exhibits other secondary behaviours.

15. Speech generating devices can be considered from the preschool phase.

Speech generating devices are important when an individual lacks effective means of verbal expression (Barbosa et al., 2018). However, vocabulary sets should be personalised, taking into account the learning disability, expressive language difficulties, the need for lexical extension and personalised special interests. These can be considered as early as the pre-school phase (Romski et al., 2023).