



How Much is Enough?

Quantifying and specifying
Speech and language therapy provision for learners with Down syndrome
in the context of the Code of Practice, 2014, and Down syndrome Act, 2022

Leela Baksi, Speech and Language Therapist, Symbol, November 2022

It's vital that learners who have Down syndrome, their families, and education staff who work with them, have access to specialist input from speech and language therapy services throughout their time in education.

This leaflet discusses:

- 1 The rationale for syndrome specific speech and language therapy
- 2 An overview of speech and language therapy needs of children and young people who have Down syndrome (this includes Early Years Settings and Further Education, potentially under 2s to 25 years old)
- 3 Identifying the speech and language therapy needs of individuals who have Down syndrome
- 4 Meeting the speech and language therapy needs of people who have Down syndrome

1 Syndrome specific speech and language therapy

Concerns about communication skills are associated with Down syndrome, so speech and language therapy plays a big part in supporting people with Down syndrome to live their best lives. People with Down syndrome often comment that 'talking is hard' and 'people don't understand me when I talk', and it is widely recognised that people with Down syndrome face particular challenges in communicating. Communication has importance in enabling people with Down syndrome to fulfil their full potential in society (Murphy et al 2018). Families see that their children's strong wish to connect and communicate can be thwarted by difficulties in using language and making oneself understood, and that their children's communication skills do not match those of other children their age. Learners who have Down syndrome (High and Robinson, 2021) and education staff are aware of communication difficulties as a barrier to participation and learning. Employers say that navigating issues with communication are key to realising potential of employees who have Down syndrome.

To realise potential, learning opportunities for people with Down syndrome must be tailored to the syndrome-specific strengths and weaknesses in communication skills, and the syndrome-specific learning style (Rondal, 2007). This means moving away from some widely used practices and teaching schemes that may not be effective when used with people who have Down syndrome, which can in turn result in these learners disengaging or making little progress. In the past this has been unhelpfully understood as lack of potential for progress, rather than recognising that teaching strategies have failed because they are not tailored to the syndrome-specific profile.

The syndrome-specific profile describes differences in how people with Down syndrome develop communication skills. There are differences in how people with Down syndrome process information and learn. Child development sets out how skills develop in different areas at different ages, but for people with Down syndrome, development does not follow the same predictable pattern, even with the best support and intervention. Skills in one area do not predict achievements in other areas (Miller et al, 1999). This is true for communication skills in relation to other skill areas, as well as between different aspects of communication skills. This 'spikey profile' combined with a 'syndrome-specific learning style' means that we cannot successfully employ the same approaches and interventions that are used routinely.

Research since the 1970s has identified that the communication skills of people with Down syndrome are not just 'delayed', lagging behind others of their age, or solely attributable to hearing loss or 'difficulties in articulating speech' (Chapman, 1997). People who have Down syndrome demonstrate stronger skills in certain areas- such as motivation to communicate, using means other than speech to get a message across (Kumin, 2008), and understanding of spoken language, which is stronger than expected, given the difficulties in using language to express oneself (Laws and Bishop 2004). There are aspects of language processing where people with Down syndrome show strengths: such as using visual representations of language: written words, symbols, and charts. These co-exist alongside many areas where people with Down syndrome experience difficulties, such as hearing and learning the sound structure of words; mastering the movements required for speech production including breath control and using voice as well as articulating sequences of sounds (Kent and Vorperian 2013); and using grammar (Smith et al 2020).

There is a great deal of variation in communication skills amongst people who have Down syndrome and each person experiences aspects of the strengths and challenges to a greater or lesser degree (Laws and Bishop 2004). So, while some people with Down syndrome chat and joke using spoken language, others use alternative means of communication like signing or communication aids to supplement speech that may be very hard to understand. Some people use lots of language, while others communicate what is important to them through strategies that are short and to the point. Some people encounter big challenges in speech production and speech clarity, while others may use speech that is fairly easy to understand but have great difficulties in remembering words.

Researchers and practitioners have identified teaching methods that capitalise on the ways in which people with Down syndrome learn. These require adjustments or differentiation to strategies typically used in classrooms, workplaces and speech and language therapy. Families and support groups, researchers and independent providers have been pushing to ensure that more people with Down syndrome have access to intervention and support that enables them to

flourish, and some NHS services and local authorities are doing strategic work to enhance the services they provide for children who have Down syndrome.

Understanding the rationale for unfamiliar and ‘new’ techniques enables staff to implement syndrome-specific interventions. Practitioners need to be knowledgeable about the evidence and theory underpinning the interventions that support learning. They need to understand the differences in how people with Down syndrome learn and know of the extensive body of knowledge about effective teaching and skill development with the syndrome-specific profile. They require robust skills in assessing the challenges, and ways forward for individuals so that they can draw up personalised plans for teaching and learning. As for all interventions, experience enhances practitioners’ effectiveness in implementing interventions, but experience of working with this client group without detailed knowledge of specific interventions does not support best practice.

Practitioners who are responsible for delivering syndrome specific intervention need a sound understanding of differences in the emergence of skills, effective support and teaching strategies, and to be familiar with key interventions. Given the impacts of speech, language and communication needs associated with Down syndrome, speech and language therapy staff play a key role in sharing information with and providing training.

2 The speech and language therapy needs of individuals who have Down syndrome

Pupils with Down syndrome will usually need speech and language therapy throughout their time in education.

- The syndrome specific profile impacting on speech, language and communication skills requires specific interventions to support sustained development across the different domains of communication.
- As cognitive skills are typically in advance of language and communication skills, these learners also require differentiated approaches to teaching and demonstrating evidence of knowledge and learning. Speech and language therapists provide guidance for education staff to assess learning and set sufficiently challenging learning goals.
- The role of the speech and language therapist includes providing expertise in teaching social communication skills and management of behaviour consequent to unmet needs which are not communicated through verbal means. This is essential to achieving social inclusion.
- Strategies and interventions must be implemented across situations where the young person spends time, including family, community and leisure settings. The need for speech and language therapy extends beyond the education setting.
- The nature of support will change over time as young people progress through life stages, meet new challenges, and attend new contexts which may include varying provisions and levels of expertise as part of their core offer.
- There is ample evidence from research studies that young people who have Down syndrome can continue to make significant progress with grammar and other aspects of communication skills with appropriate intervention.

Speech and language therapy intervention must take into account syndrome specific perspectives in order to be effective

Speech and language therapists working with this population must have sound knowledge of syndrome specific approaches and their rationale. Learners with Down syndrome will receive speech and language therapy across a range of settings by speech and language therapists who may not be specialists in Down syndrome. We therefore recommend that speech and language therapy provision for clients with Down syndrome is overseen by speech and language therapists with specialist knowledge and skills in working with this client group. Specialists should guide and support other speech and language therapy staff. Specialists should also assess and advise on speech and language therapy needs, and design and deliver intervention for clients with Down syndrome who require more expert management.

These therapists must be equipped with specialist skills and knowledge that is up to date and comprehensive, and require an in depth understanding of syndrome-specific interventions, assessment issues, underpinned by critical appraisal of syndrome-specific research.

***Indirect* input, where strategies are carried out by education staff or others, requires ongoing support from speech and language therapy.**

Speech and language therapy strategies must be implemented throughout the day and across activities to support learners who have Down syndrome to participate, to learn, and to demonstrate their knowledge. Speech and language therapy cannot be viewed as a standalone activity or solely carried out by speech and language therapy staff.

Burgoyne, 2022 writes: 'Therapists should provide parents and educators with training so that they understand children's learning needs, and model teaching activities with the child. It is clear that with high-quality training and support, educators (including teaching assistants and special education teachers) can effectively deliver structured language intervention to children with DS'.

When speech and language therapists recommend and specify strategies for others to implement, it is essential that they also provide support, monitoring and training essential to ensure accurate implementation and to realise best outcomes. This may be achieved by the speech and language therapist working as part of the school team, for example in specialist settings. In situations where the speech and language therapists visits the setting, an appointment should be made to follow up recommendations within 2-4 weeks.

Some interventions require a higher level of technical expertise and need to be carried out as *direct* input by speech and language therapy practitioners with training and experience of delivering these interventions.

Most pupils who have Down syndrome will require implementation of a number of speech and language therapy interventions which rely on practitioners' training in and experience of specific interventions, and/or interventions where precise feedback and differential reinforcement is required. This might include, for example, developing motor and articulatory skills for specific

speech sounds; using visual supports such as Shape Coding TM; teaching the phonological, semantic and syntactic aspects of vocabulary; addressing social communication skills in a group setting responsive to issues as they arise.

Burgoyne, 2022 writes: The amount of intervention matters: children with DS who receive more frequent intervention make greater gains in learning. It is therefore vital that SLTs deliver direct therapy regularly, complemented by daily support for language learning at home and in school.

3 Identifying the speech and language therapy needs of individuals

Speech and language therapists with specialist knowledge of Speech, Language and Communication Needs (SLCN) and recommended interventions for learners with DS should determine speech and language therapy requirements for individuals, taking into account the characteristics of settings, as well as individual presenting needs.

The Code of Practice states: Provision must be detailed and specific and should normally be quantified, for example, in terms of the type, hours and frequency of support and level of expertise.

The amount of input from speech and language therapy services required for each individual will be dependent on:

- The specific needs of the individual and challenges they face, and the complexity of interventions required
- The skills and experience of those supporting them
- The availability of time for preparation, making resources, and accessing training and information- where this is limited, speech and language staff will need to provide more intensive support
- The extent to which strategies and interventions can be accommodated and implemented in the education setting and other settings where the individual spends time.

Recommendations for individuals, as set out in the Code of Practice, cannot be based on or constrained by blanket recommendations for age groups or settings*. Guidance for speech and language therapists from the Royal College of Speech and Language Therapists (Howe et al, 2016) states 'Models of intervention, facilities and resources recommended should relate *directly to the needs of the child or young person and not the level of services available*'.

It is the responsibility of the lead speech and language therapist to identify frequency, duration and total time requirement to meet the speech and language therapy needs of individuals. This is usually set out in advice for Education Health and Care Plans.

*The All Party Parliamentary Group on Down syndrome Good Practice Guidelines for Education (2012) state 'SALT provision to secondary schools should involve at least half termly visits to monitor progress, advise on strategies and supervise implementation of language programmes tied into the curricular needs as well as advising on social language skills needs and TA led group activities to develop these'. This was specified taking into account trends and practices at that time, seeking to improve availability of speech and language therapy.

Recommendations should specify input to:

- Contribute to review of EHCP
- Provide support, expert advice, and training to school staff
- Design and develop resources for speech and language therapy interventions
- Support and monitor implementation of interventions by others in a timely manner: that is, ensuring that practice conforms to planned activities.
- Execute direct work by speech and language therapy staff with individual learners.

4 Meeting the speech and language therapy needs of this population

The development of robust, evidence based syndrome specific local pathways in Local Offers that set out speech and language therapy and related provision specifically for young people who have Down syndrome will reduce the need to commission speech and language therapy on a case-by-case basis for individuals.

We recognize that commissioning specialist speech and language therapists to deliver speech and language therapy for named individuals is an unsustainable and inefficient strategy for meeting the needs of this population.

The 2014 SEND code of practice sets out that local authorities must publicise a Local Offer, which is usually published on the local council's website. The guidance says it should include 'provision for children and young people with low-incidence and more complex SEN' (Down syndrome is categorised as a low incidence disability), and 'specialist services for children and young people with SEN or disabilities who require specialised, longer term support', including speech and language therapy. Several local authorities have published specific information about Down syndrome, some including speech and language therapy provision (see, for example, www.leicspart.nhs.uk/wp-content/uploads/2020/02/LPT-Combined-care-pathway-for-DS.pdf , accessed October 2022), but this is not the case in all local authorities.

The Down Syndrome Act 2022 creates a legal obligation to create and consider syndrome specific practices in service provision: 'The Secretary of State must give guidance to relevant authorities on steps it would be appropriate for them to take in order to meet the needs of persons with Down syndrome in the exercise of their relevant functions....Relevant authorities must have due regard to the guidance in the exercise of their relevant functions.'

When designing speech and language therapy services that implement syndrome specific responses, individual needs can be met in various ways.

- Speech and language therapy can be delivered in education settings, or elsewhere, such as meet-ups for families of young children with DS, out of school clubs and youth groups set up for this purpose. When education staff are able to attend either supporting or observing activities, strategies and goals are shared across settings,
- Families and other providers such as parent support groups, early intervention services, and youth services have been instrumental in establishing such provision in alternative settings.

- Receiving speech and language therapy in a group with learners with compatible needs and interests can provide enhanced opportunities for learning, as well as supporting social skills and self esteem.

The shortage of speech and language therapists across the workforce, and limited availability of those with specialism in Down syndrome has been addressed by initiatives that provide intensive and robust training in syndrome specific speech and language therapy interventions to workers a strong interest in expanding provision with relevant experience.

There are examples from across the UK of initiatives that deliver syndrome specific intervention.

These include:

- Parents support groups, some speech and language therapist services and schools, and charities such as Down Syndrome Scotland have increased workforce capacity by securing training for suitable candidates to work as speech and language therapy support staff carrying out syndrome specific intervention.
- Portage workers undertaking additional training and then working with specialist speech and language therapists to provide group speech and language therapy sessions for pre-school children, along with home visits for those families unable to access group sessions.
- Teaching assistants with relevant experience and skills undertaking additional training to carry out speech and language therapy activities with several pupils who have Down syndrome in a mainstream secondary school.
- Annual training days for classroom teams in mainstream schools who have a pupil with Down syndrome in their class, attended by teaching assistants, class teachers, and SENCOs. Key topics to cover are set out in detail in the APPG-DS Good Practice Guidelines for Education 2012 and include: syndrome specific approaches to literacy, numeracy, differentiating the curriculum, and realizing the advantages of placement in a mainstream setting for these pupils.
- Specialist support services providing training and visits to enable schools to implement the The Reading and Language Intervention for Children with Down Syndrome (RLI)
- Setting up holiday camps, Saturday meet ups, or coming out of school to attend groups with other children and young people who have Down syndrome where syndrome specific Speech and language therapy intervention is carried out by staff with training and experience in this.

This updates information in the booklet 'How much is enough?' developed with the DSA dated 2006 and available on the Down Syndrome Development Trust website.

www.symbolconnect.co.uk

References

- Murphy et al (2018) Communication as a human right: Citizenship, politics, and the role of the speech-language pathologist. *International Journal of Speech-Language Pathology* 20 (1): 1-5
- High and Robinson (2021) Graduating University as a Woman with Down Syndrome: Reflecting on My Education. *Social Sciences* 10: 444.
- Rondal (2007) Chapter 5 Language Rehabilitation. in Rondal and Rasore Quartino (Eds) *Therapies and Rehabilitation in Down syndrome* John Wiley
- Miller (1999) Improving the Communication of People with Down syndrome. Miller Leddy Leavitt (Eds) Paul H Brookes
- Chapman (1997) Chapter 10 Language Development. in Pueschel and Sustrova (Eds) *Adolescents with Down syndrome* Paul H Brookes
- Kumin (2008) *Helping Children with Down syndrome Communicate Better*. Woodbine House
- Laws and Bishop (2004) Verbal deficits in Down's syndrome and specific language impairment: a comparison. *International Journal of Language and Communication Disorders* 39:4, 423-451
- Kent and Vorperian (2013) Speech impairment in Down syndrome: A review. *Journal of speech language and hearing research* 56 (1):178-210.
- Smith et al (2020) Children with Down syndrome can benefit from language interventions; Results from a systematic review and meta-analysis. *Journal of Communication Disorders* 85: 105992–105992.
- Burgoyne (2020) Language Intervention for Children with Down's syndrome. *Bulletin, Royal College of Speech and Language Therapists* August 2020 10-13
- Code of Practice (2014) *Special educational needs and disability code of practice: 0 to 25 years*. Department of Education and Department of Health
- Howe et al (2016) *Guidance for Speech and Language Therapists on their roles and responsibilities under the Children and Families Act 2014 and associated Code of Practice*. Royal College of Speech and Language Therapists Position Paper RCSLT: London available at www.rcslt.org/wp-content/uploads/media/Project/RCSLT/childrens-families-act-guidance.pdf accessed October 2022
- APPG-DS Good Practice Guidelines for Education (2012) All Party Parliamentary Group on Down Syndrome, Education Advisory Group, available at assets.cdn.down-syndrome.org/files/reports/appg-down-syndrome-education-guidelines-report-2012.pdf accessed October 2022
- Down syndrome Act 2022 www.legislation.gov.uk/ukpga/2022/18/enacted accessed October 2022