

Down Syndrome Toolkit for Paediatric Speech and Language Therapists



Lancashire &
South Cumbria
NHS Foundation Trust





What is this Toolkit?

There is a large research literature on the development of speech and language in children with Down syndrome. Most of this literature explores the patterns of development among children and young adults and has identified some of the reasons for the delays that most experience. A smaller number of studies have investigated effective interventions. Any speech and language therapist who is providing a service to a child or young person with Down syndrome should have a working knowledge of the key information from this research as it is relevant to delivering effective intervention.

This Toolkit provides an overview of this research to inform any SLT working with a child or young person with Down syndrome (Age 0-19) and references to further reading. It also lists training courses that are available for those wishing to gain further knowledge.

The Toolkit is meant to be read alongside any care pathway documents your team has and aims to help therapists to understand the specific needs of this group of children. It aims to add additional information and support to help tailor assessment and input.

How this project came about:

Lancashire and South Cumbria Foundation Trust is made up of six localities based across Lancashire, which employs over 90 Speech and Language therapists and assistants. Many of the team were inspired by Dr Kelly Burgoyne's article in the Bulletin (Burgoyne, 2020) regarding the evidence base around interventions with children with Down syndrome. Following many discussions, we completed a survey of staff and found that most staff felt they lacked the knowledge to support these children and their families. Having had some contact with Professor Sue Buckley previously the team asked her to complete a presentation about the new research in the field, which also received very positive feedback. We subsequently formed a working party with specialist and newly qualified SLTs to write this Toolkit. Our aim was for staff to have a reference point for up-to-date research, information, intervention, target setting, which could be added to. With the help of both Professor Sue Buckley and Dr Kelly Burgoyne giving us their feedback and time we managed to bring together the Toolkit, which we do hope that you find useful. The Toolkit is intended to represent a working document to be updated and refined as new research evidence and understanding is available.

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Developmental milestones

There are currently no nationally recognized milestones for children with Down syndrome. Below, we have reproduced milestones reported in research (Tables 1-3) which you may find useful including milestones for vocabulary development. As shown in the tables, just as with all children, there is a great deal of individual variation in the age when different children with Down syndrome achieve the same skill. All children with Down syndrome will be delayed relative to children who are developing typically, but some will be more delayed than others. It is also important to note that not all aspects of development will be equally delayed; some aspects of development may be progressing faster or slower than others. This highlights the need for an **individualized approach to therapy and support**. There is also the need to take into consideration health problems referred to later in the co-existing medical conditions section, which may affect development, causing greater variation. Many parents may be provided with the Early Support Developmental Journal for babies and children with Down syndrome, which is a set of charts that families use to record what their child is able to do—now available online see references. This journal can be a good way for parents to keep track of progress.

Table 1: Average and Range of ages (months) at which Children with Down syndrome meet Typical Developmental Milestones in Motor, Communication, and Personal and Social Skills (adapted from Buckley & Sacks, 2001).

Area of Development	Milestone	Children with Down Syndrome		Typical Milestones	
		Avg Age	Age range	Avg Age	Age range
Gross Motor Skills	Holds head steady in sitting position	5m	3-9m	3m	1-4m
	Sits alone	9m	6-16m	7m	5-9m
	Stands alone	16m	12-38m	11m	9-17m
	Walks alone	23m	13-48m	12m	9-17m
Fine Motor Skills & Eye/hand Co-ordination	Follows object with eyes	3m	1.5-8m	1.5m	1-3m
	Reaches out & grasps objects	6m	4-11m	4m	2-6m
	Passes objects from hand to hand	8m	6-12m	5.5m	4-8m
	Builds a tower of two 1" cubes	20m	14-32m	14m	10-19m
	Copies a circle	48m	36-60m	30m	24-40m
	Puts a peg in peg board two or more times	23m	17-36m		



Communication skills	Turns to sound of voice	6m	3-8m	4m	2-6m
	Babbles dada, mama	11m	7-18m	8m	5-14m
	Responds to simple verbal instructions	16m	12-24m	10m	6-14m
	First words/gestures with meaning	18m	13-36m	14m	10-23m
	Shows needs by word/gesture	22m	14-30m	14.5m	11-19m
	A few two word phrases	30m	18-60m+	24m	15-32m
Personal & Social Skills	Smiles when touched and talked to	2m	1.5-4m	1m	1-2m
	Drinks from cup/ uses spoon or fork	20m	12-30m	12m	9-17m
	Urine control by day	36m	18-30m	24m	14-36m
	Bowel control	36m	20-60m	24m	16-48m

Table 2 Expressive vocabulary development. DSEI longitudinal study - CA chronological age, MA mental age (Baxter, Hughes, Buckley 2011)

	Mean CA 23.5 m MA 14.7m N 16		Mean CA 36 m MA 21.7m N24	
	mean	range	mean	range
Sign only	35	4-137	80	8-240
Sign and word for same item	20	0-92	53	1-210
Word only	5	0-21	38	0-213
Total vocabulary	60	4-206	171	20-411

Data on vocabulary development from a study of 40 children receiving early intervention, collected by Down Syndrome Education International, illustrates the enormous variability in early vocabulary for these children with Down syndrome referred to in table 2 here. The expressive vocabulary of monolingual English-speaking typically developing children aged 22 months has also been found to vary considerably, from 77-518 words (Stokes & Klees 2009).



General Language skills

In children with Down syndrome, receptive language is typically stronger than expressive language, and vocabulary is stronger than syntax (Chapman & Hesketh, 2000). Strong evidence (Abbeduto et al 2020, Jarrold et al 1999, Kumin et al 1994) suggests that phonology, expressive vocabulary, receptive and expressive syntax, and some pragmatic aspects of language are impaired beyond expectations for nonverbal cognitive level. Possibly indicating a form of language disorder relative to their non-verbal mental age (Buckley 2002; Laws 2003; Vicari 2000). Although most children are delayed in the onset of their first words, others have found that some children start using words at a similar age to typically developing children (Chapman 1997). However, the gap in language attainment between children with Down syndrome and their typically developing peers, even those of the same non-verbal mental age, tends to widen with increasing age.

General Speech development

Most children and young people with Down syndrome experience difficulties with speech clarity and there are a number of reasons why this might be the case (Kent & Vorperian 2012) :

- Differences in anatomy and physiology (Smaller and narrow upper jaw and high palatal arch, which reduces the amount of space for the tongue).
- Decreased strength in oral facial muscles.
- Hearing problems can result in difficulties in hearing, processing and producing the sounds.
- Difficulties with phonological acquisition. Emergence and mastery of consonant phonemes can be a protracted process, with substantial individual variability.
- Also prosodic difficulties: rhythm; intonation; lexical and emphatic stress.
- Children with Down syndrome learn and process information at a slower rate.
- Difficulties with working memory.

Cleland et al (2007) concluded that speech is particularly impaired in children and young people with Down syndrome. In their study they found that all the children in their study showed at least one atypical or non-developmental speech error concluding that children and young people with Down syndrome present with speech disorders characterized by atypical errors alongside many developmental errors. The cause of the speech disorder in Down syndrome remains unclear (Kent & Vorperian (2021). However, anecdotal reports that the more unintelligible children are not necessarily the most cognitively or linguistically impaired was confirmed by the lack of any correlation between their speech measures and either cognitive or language measures in their study.



Pre-linguistic communication

Which typically means the development of eye contact, joint attention, anticipation, pointing/reaching, facial expression/body language, social gestures/signs, turn-taking /social routines and sequences, babbling/symbolic noises and imitation, which form the foundation of speech and language development.

There has been a number of research studies focusing on pre-linguistic communication comparing children with Down syndrome to typically developing peers (TD). Children with Down syndrome typically have difficulties with components of joint attention (the ability to coordinate attention between people and objects), such as reciprocal eye contact (Berger, 1990). Despite this, children with Down syndrome are as likely to initiate and respond to the joint attention initiations of others as are their typically developing (TD) peers (Sigman et al., 1999).

Mason-Apps et al 2018 found responses to joint attention and non-verbal mental age at 18 months predicted longitudinal language outcomes a year later in children with Down syndrome. In contrast, nonverbal requesting appears to be an area of challenge for children with Down syndrome. Several investigators have found that children with Down syndrome make fewer nonverbal requests than typically developing peers (Sigman et al., 1999).

Commenting and requesting are skills often associated with better linguistic communication and therefore delays in these nonverbal communication skills may also contribute to the well-documented language deficits in Down syndrome. Young children with Down syndrome demonstrate a relative strength in the use of gestures. Franco and Wishart (1995) demonstrated that the frequency and variety of gestures produced is comparable if not higher in Down syndrome relative to younger TD children with similar overall communicative ability.

However, individuals with Down syndrome integrate gestures and language differently than TD children. Children with Down syndrome seem to primarily use “equivalent” combinations, such as waving goodbye and saying “bye,” whereas TD children are more likely to use “complementary” combinations, such as pointing at a bird and saying “bird,” and “supplementary” combinations, such as signing “more” and saying “cookie” (Zampini & D’Odorico, 2011).

This may well have implications for developing a wider vocabulary and learning to combine words into longer phrases.



Additional factors to consider during assessment

Co-occurring medical conditions

This is not an exhaustive list, but lists some of the most common conditions: For further details see <https://www.dsmig.org.uk/information-resources/by-topic/>

Almost one-half of babies with Down syndrome have congenital heart disease (CHD), the most common type of birth defect. Sometimes, the heart defect can be detected before birth, but testing after birth is more accurate. Some heart defects are minor and may be treated with medication, but others require surgery.

More than half of children with Down syndrome have vision problems, including cataracts (clouding of the eye lens) that may be present at birth. The risk of cataract increases with age. Other eye problems that are more likely in children with Down syndrome are near-sightedness and rapid, involuntary eye movements. Glasses, surgery, or other treatments usually improve vision.

Hypothyroidism, when the thyroid makes little or no thyroid hormone, occurs more often in children with Down syndrome than in children without Down syndrome. The thyroid is a gland that makes hormones the body uses to regulate things such as temperature and energy. Taking thyroid hormone by mouth, throughout life, can successfully treat the condition.

Children with Down syndrome are more likely to have epilepsy, a condition characterized by seizures, than those without Down syndrome. The risk for epilepsy increases with age, but seizures usually occur either during the first 2 years of life or after the third decade of life. Seizures can usually be treated and controlled well with medication.

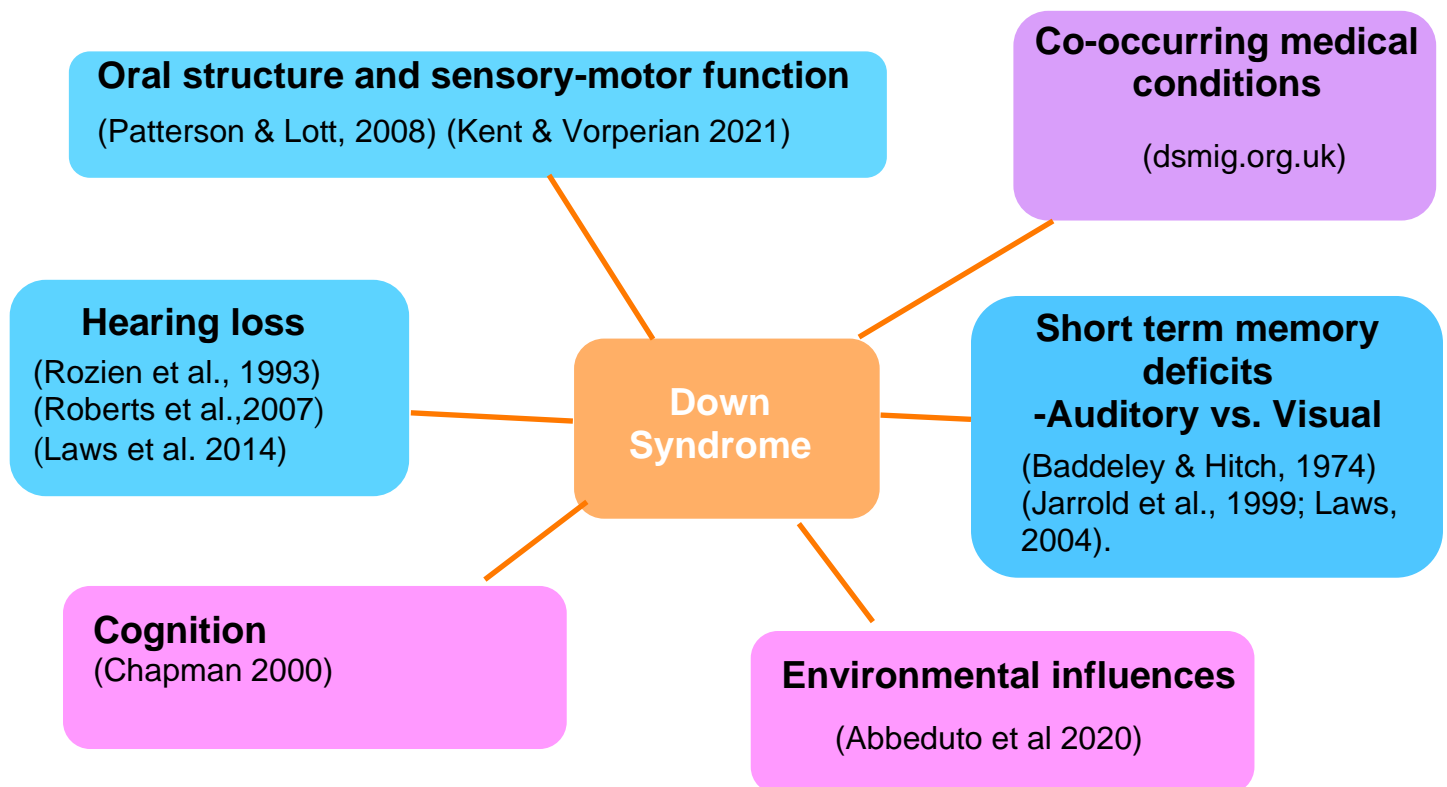
Many children with Down syndrome have disrupted sleep patterns and often have obstructive sleep apnea, which causes significant pauses in breathing during sleep.

Children with Down syndrome may develop teeth more slowly than other children, develop teeth in a order, develop fewer teeth, or have misaligned teeth compared to children who do not have Down syndrome. Gum disease (periodontal disease), a more serious health issue, may develop for a number of reasons, including poor oral hygiene.



Influences on Speech and language development

Many factors influence the speech and language development of children with Down syndrome. Figure 1 below provides a visual overview of the factors which research has identified as important in the speech and language development of individuals with Down syndrome. These are discussed in more detail below.



Hearing loss:

Approximately two-thirds of children with Down syndrome experience conductive hearing loss, sensorineural hearing loss, or both (Roberts et al, 2007). Hearing loss can affect one or both ears and range from mild to profound. Children with Down syndrome are particularly susceptible to otitis media (OME), possibly due to narrow auditory canals and cranial facial differences. Otitis media has been found to occur in 96% of young children with Down syndrome. OME-associated hearing loss possibly presents an extra risk factor for children with Down syndrome because they are already at risk for language difficulties. In fact, hearing loss is related concurrently to difficulties in comprehension of grammatical morphemes and vocabulary for individuals with Down syndrome. Children with Down syndrome with moderate to severe hearing loss between the ages of 2 and 4 may go on to have more impaired receptive vocabularies, language comprehension, expressive language and articulation difficulties compared to those children with Down syndrome who have normal hearing (Laws & Hall, 2014). It is important to understand the **hearing profile** of the children you are working with and follow the recommendations set out in your team's care pathway as HI can have a significant effect on speech and language development.



Cognition and short-term memory

Individuals with Down syndrome typically display IQs between 30 and 70, with a mean near 50 (Chapman, 1999). Impairments are greater, however, in some domains of cognition.

Short-term memory for auditorily presented sequences of speech sounds (i.e., phonological memory) is an area of particular challenge, with poor performance on tasks such as digit span or non-word repetition relative to performance on tasks measuring visuo-spatial short-term memory or measures of nonverbal mental age. Impaired phonological memory skills (measured with non-word repetition) may be associated with poorer language comprehension, reduced mean length of utterance (MLU), and reading difficulty in children and adolescents with Down syndrome (Laws, 1995, 2004a,b).

Short-term memory difficulties have also been linked to language difficulties in this population (Chapman 2001; Laws 2004). It is therefore essential that any SLT has an **understanding of the learning profile** of the children and young people they work with and keep in mind the importance of presenting tasks in a variety of modalities rather than relying exclusively on auditorily presented tasks.

Oral structure and function

Speech production of individuals with Down syndrome may be related to differences in oral structure and function (Miller & Leddy, 1998; Stoel-Gammon, 1997). Structural differences include a small oral cavity with a narrow high arched palate. These differences are thought to account, in part, for poor speech intelligibility due to dysarthric factors such as reduced speed, range of motion, and coordination of the articulators. In addition, compared with typically developing children, children with Down syndrome show differences in the structure of the lips, tongue, and velopharynx, and are less skilled at speech motor functions (Kent & Vorperian 2021) and coordinated speech movements involving the lips, tongue, velopharynx, and larynx (Barnes, Roberts, Mirrett, Sideris, & Misenheimer, 2006).

It is important to recognize the effect practice and use of spoken language and vocabulary size has on speech development, rather than attributing speech difficulties to physical differences alone. The main point is we always look for Down syndrome physical factors as explanations and ignore the influences of development in all areas. The effect of delays, ways children are talked to, and effects of practice is too often forgotten.

This is stressed in a recent review chapter on Language Development in Down Syndrome (Abbeduto, Arias-Trejo, Thurman, Ramos-Sanchez, del Hoyo Soriano 2020). They state *'From a clinical perspective, the shaping of language learning by the environment suggests that improvements in language in children with Down syndrome are possible by systematizing, enriching, and optimizing their environments.'* P23 online version.



Service provision and role of the Speech and Language Therapist when working with children with Down syndrome.

Role of the SLT:

An SLT's role involves working with children, their families, and educators to develop individualized programmes of therapy and support for those with speech, language and communication needs. Our role is to assess the children on our case load on a regular basis and, in collaboration with parents and education providers, develop an appropriate intervention plan based on the individual child's needs.

Speech and language therapy provision might include the opportunity for face to face/virtual intervention when this is indicated from the assessment, for example, to work on specific speech intervention or grammar development. But direct therapy from an SLT will not be sufficient on its own. It is vital that parents and educators are supported to understand that they play a vital role in supporting communication development. SLTs should **empower** those around the child to be the best communication partners they can be. We need to establish early on the importance of **collaboration** and working together not only during intervention, but also target planning. This should be supported by appropriate **training** for both parents and school staff, and regular monitoring and support. The child's communication goals should be **incorporated** in to their Individual Education Plan and **integrated** into classroom and home activities. We can support this with demonstration sessions through **modelling**, and through information packs and/or videos. In order that parents and other family members may play their part it is important that the therapist maintains **contact** with the family and the school through direct liaison and written reports.

In relation to children/young people with learning disabilities not specific to Down syndrome, Brady et al 2016, Porter et al 2001, Chadwick et al 2018 support the point that management needs to be holistic and consider the child, the environment and communication partners.

Training for speech and language therapists working with children with Down syndrome

Any speech and language therapist who is providing a service to a child or young person with Down syndrome should have a working knowledge of the key information from this research as it is relevant to delivering effective intervention.

This Toolkit provides an overview of this research to inform any SLT working with a child with Down syndrome and references to further reading. It also lists training courses that are available for those wishing to gain further knowledge, which can be found after the references.

We recommend that each NHS service has a clinical lead who has taken further training and has significant experience of working with children and young people with Down syndrome. This clinical lead should provide supervision and training for the therapists in his/her team who are working with a child or young person with Down syndrome.



Referrals:

How referrals are made can vary across localities and will be triaged as appropriate with the guidance specified by your team and the commissioning guidelines. A service should be provided to children and young people from 0-19 years who have an identified communication and/or eating, drinking swallowing (EDS) need. Due to children with Down syndrome being highly likely to have difficulties with Speech, language and communication needs an assessment by an SLT should always be provided to a child with Down syndrome as standard. Research has shown that early intervention pre two years of age can also have a positive effect on outcomes in this group (Warren, Bredin-Oja, Hahn, Brady 2020) so an early referral and assessment should be offered.

Initial assessment:

The first part of any initial assessment should be a detailed case history, which maybe a generic one or one which was specifically written for children with Down syndrome. A template case history form can be found in this Toolkit at the end of this document.

In the majority of cases the initial assessment should lead to the:

- Identification of the child's needs (be this Speech, language, communication, eating/drinking difficulties or a combination).
- Clarification of the impact on the child/young person.
- Agreement on the nature of intervention needed, if appropriate.

The initial assessment may be completed remotely (over telephone or video call) or during a face to face consultation, and may require more than one appointment especially in the case of telephone consultations when a further appointment will be needed. In addition to discussion with the parent, the therapist should always have direct observation/interaction/assessment with the child to support safe clinical decision making. By the end of the initial assessment:

- First definitive advice/treatment should be given where possible. This must be specific to the individual child's needs, based on the assessment undertaken.
- The advice should be sufficient to enable the family and/or school to manage the child's needs, either long term or until regular intervention commences.
- Leaflets/handouts and links to websites and other sources of support (including Down syndrome support groups where relevant) may be given as part of a conversation which tailors the advice to the child's specific needs.
- Discharge should be discussed in detail if no current needs have been identified and make it clear that parents/education settings will be advised to re-refer when concerns arise.



Agreeing the involvement plan:

At the start of the involvement there should be discussion with the family and school / early years setting around the benefits and risks of any intervention, and of not intervening. Every effort should be made to ensure effective communication with parents, school/nursery staff taking into account any language, learning or literacy needs.

SLTs and families should agree the timing and nature of the involvement plan, taking care to support families and other professionals to have realistic expectations of what the service will offer. It would be appropriate from the start of intervention to discuss the child and young person's needs that cannot be met by the service and be able to signpost parents to other services which could offer them additional support.

- Outcomes for the intervention should be identified and agreed with the family/school and/or child/young person, and should be functional
- Goals leading to the outcome should be SMART and appropriate to the relevant care pathway.
- It should be made clear in discussion whether the outcome is likely to be for the child to achieve a level of speech and language / EDS which is within the typical range, or for the child to reach their own individual potential.
- An open conversation should take place around the length of the intervention and when and how the involvement might cease, including discussion of discharge criteria.
- We know that children with Down syndrome are likely to have long term needs so parents/schools should be made aware that involvement will be episodic and goal orientated, rather than continuous and open ended. However, because the referral system is open their needs can be reassessed at any time and this may be particularly pertinent at times of transition when a new set of communication partners may need training and coaching.
- Expectations regarding each partner's responsibilities in the process of therapy should be explored and agreed so that partners understand how their engagement will contribute to the success of the intervention.
- This should include discussion of what factors will facilitate or hinder the success of the involvement
- Where children are seen in school, agreement should be reached on how frequently and by what means parents will be involved/consent renewed
- Recording of regular input by partners should form an integral part of the delivery and evaluation of the involvement plan e.g. through a recording sheet as part of a programme, or a notes sheet for parents to record their activity and the child's responses
- Partners should be made aware of the service policy around failure to attend appointments or lack of engagement with the intervention. It is important that services support families to access/engage with services e.g. liaison with key professionals, use of interpreters etc.



Involvement (Linked to care pathways):

Appropriate approaches to involvement will be determined through clinical judgement, discussion with the family, and with reference to the relevant care pathway of your service and the evidence base (which is detailed in this Down Syndrome Toolkit). Involvement may be virtual and/or in person.

All approaches to intervention will have the ultimate goal of reducing the impact of any difficulty and enabling those around the child and young person to meet their communication needs, especially where difficulties are likely to be long lasting or persisting. In every case the therapist should follow a clear process of clinical reasoning which identifies the best approach to achieving these goals. This should take account of school and family circumstances and needs at the time. Every effort should be made to implement this best approach (clinical decision making based on the best available evidence in addition to taking account of the context and perspective of the child/family).

If this best approach cannot be implemented, because of e.g. lack of engagement from partners etc., the therapist should adopt a step down approach to consider what would be the next best approach to maximize success in achieving therapeutic aims. This step down approach should continue until an agreement is reached which will enable the best possible outcomes. Ultimately this may be at the level of offering advice and supportive strategies.

Most interventions for communication will involve a combination of the approaches below and please see section on intervention and therapy, for more information and resources):





- Direct therapy – therapist or assistant working with the family / child individually or in groups. This will be focused on specific aspects of speech/language/ communication, aiming to bring about change/development in the child’s own communicative ability e.g. speech sound work, specific work on syntax, direct work on inferencing etc.
- Indirect therapy – carried out by a parent and/or appropriately trained professional colleague e.g. SLTA, teaching assistant. This may have a focus on improving the child’s own specific communication skills, but is likely to be in a familiar context, thereby also addressing functional aspects of communication relating to the interaction of the child and the environment. The aim will therefore also be to reduce the impact of the condition. This may also involve coaching of parents to improve interaction with the child to facilitate the development of communication
- Environmental modification – this will focus on creating a more communication friendly/supportive environment for the child in order to reduce the impact of the communication difficulty. It may involve strategies to change how adults around the child interact, as well as addressing e.g. classroom routines and approaches and the physical environment.
- Training – may support direct or indirect intervention, or may be focused on enabling others to provide the optimum communicative environment to allow the child to maximize their communicative potential and reduce the impact of the difficulty. This is a key part of the service offer and should be fully used to ensure maximum effectiveness of any intervention
- Advice and strategies – these may be individual to the child or may be more general. Parents and staff in settings may be directed to the service website (and other appropriate websites) for this support.

All of these interventions may also be used in management of EDS, aiming to improve oral-motor skills and create the best conditions for safe and social mealtimes

Involvement plans, advice sheets and reports should be prepared on the agreed templates and be clear and concise. In this Toolkit there is a specific formulation for target setting for children with Down Syndrome at the end of this document. This formulation is in line with expert recommendations that identify the need for separate targets for the four components of speech and language skills - communication, vocabulary, grammar and speech work, for each child. As detailed in this Toolkit, literacy and speech and language skills are closely interrelated and intervention planning and activities should take literacy into consideration. Therefore, when setting targets a joint approach with the teacher can be best practice e.g., linking with class topics, phonics sessions, etc.

Any changes to the involvement plan should be discussed with parents. Where children are accessing therapy/ programmes in school, liaison and parental consent should be sought as a minimum once a year.

Where a child has an Education and Health Care Plan (EHCP) and changes are made to the advice given on the plan, an amended plan should be agreed with parents, sent to the local authority and copied to the parents.



Further information:

<https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/send-reforms-toolkit.pdf>

<https://www.rcslt.org/wp-content/uploads/media/docs/Covid/EHC-needs-assessment-and-plans-temporary-changes-RCSLT-summary-1-May-2020.pdf>

Evaluation reports should be written on reasonable request, or where it is necessary to update partners on discharge or a change of management/involvement plan. These should be concise and meaningful to the recipient.

Follow up (review) appointments (linked to pathways)

Follow up appointments should be offered as part of active involvement where there are clear clinical indications that further involvement is needed

This may be

- where the initial plan is based on a hypothesis which needs to be confirmed and response evaluated
- where the intervention consists of indirect, but ongoing, care plans requiring evaluation, monitoring and support, prior to further planned intervention
- where a period of consolidation and generalisation is needed as part of ongoing intervention

Follow ups can be offered as and when necessary. Intervention and follow up can continue as long as the child has an identified need.

Discharge:

As mentioned previously episodes of cares are offered and if at that time the care is complete than a discharge takes place. However if any new needs arises the child can be reassessed and a new episode of care opened.

Discharge will be initiated by the clinician if:

- The aims of involvement have been achieved and no further areas for intervention have been identified.
- Involvement of the service(s) is no longer necessary as school staff, family and carers have been trained and are confident and competent in using strategies to support their child's communication skills.
- The child is being transferred to a specialist centre or other service(s)

Please see section on **target setting** and the formulation sheet we have devised to help plan intervention.



Interventions and therapy approaches

This is not intended to be an exhaustive list of all of the interventions/approaches that can or should be offered to children with Down Syndrome. Instead it provides some examples of interventions and approaches you may wish to draw upon. It is important to note that, as yet, there is limited research evidence to support the benefits of some of these approaches specifically for children and young people with Down syndrome. The suggestions provided below draw on experiences of practitioners, research on factors influencing the typical development of speech and language, on evidence of approaches that are effective for other groups of children, as well as on studies of effective interventions for children with Down syndrome. A useful reference for evidence informed interventions and approaches to support children with speech, language and communication needs is the What Works database (see <https://ican.org.uk/i-cans-talking-point/professionals/tct-resources/what-works-database/>)

The interventions are organized into:

- a) General approaches which are useful to support language and communication at all ages/stages.
- b) Specific approaches for particular aspects of language and communication.

Suggestions for further information and resources are provided and, where relevant, we include a reference to relevant research to support the approach.

Every child is unique and will develop at their own pace. It is essential that any intervention is based on a partnership between parents and other communication partners and is always rooted in what is relevant and functional for that child (see section on target writing). Intervention should be applied across different contexts to improve **generalisation**. Frequent repetition and practice is important to **consolidate** learning. Note that **imitation** is a relative strength: Children will benefit from being involved in communication interactions with peers and adults, and from social interaction in therapy approaches.

Feeding: (Where commissioned)

Babies with Down syndrome typically have low or “floppy” muscle tone (Kumin, Goodman & Councill, 1991) This not only affects the muscles of the arms and legs but also causes the muscles in the neck, face and mouth to be weaker as well. Feeding problems associated with low muscle tone include:

- Difficulty latching on to the breast or teat and therefore not gaining enough suction to express milk from the teat/breast.
- The mouth may be less alert or ready for feeding.
- Swallowing air leading to tummy cramps/ discomfort during feeding.
- Loss of interest in feeding before the feed is finished.
- Problems with moving on to spoon feeds and different food textures.



The combination of reduced oral space and limited control also contribute to feeding problems in infants with Down syndrome. There can typically be a small oral cavity and the palate is usually flatter with a high arch in the midline and the nasal passages are narrowed. The combination of reduced oral space and low muscle tone can result in tongue protrusion

In addition, children with Down syndrome can be born with additional medical conditions such as cardiac problems (aprox. 40%), which can cause additional fatigue that impacts on feeding.

A useful guide to supporting feeding has been produced by Down Syndrome Ireland called Supporting Feeding & Oral Development in Young Children, which is a useful guide for parents you may like to share. The link:

[feeding_oral_development.pdf \(downsyndrome.ie\)](https://www.downsyndrome.ie/feeding_oral_development.pdf)

General approaches and intervention

Many of the approaches below should be made use of in therapy/intervention for children with Down syndrome. It is important to note that naturalistic approaches will not be sufficient to promote learning: Structured activities and supports should be in place alongside naturalistic learning.

Intervention/Approach	Evidence/Research	Information and Resources
<p>Naturalistic approaches: Approaches which involve parents and other communication partners interacting with the child during every day routines while using techniques such as modelling/teaching.</p> <p>There are benefits of parent and teacher/TA training as well as SLT – supervised intervention. Involving parents and other communication partners in delivering therapy/intervention supports frequent practice across contexts (which is important for consolidation and generalisation).</p>	<p>Smith, Hokstad and Nass, (2020) JCD Systematic review and meta-analysis of existing language interventions in Down syndrome.</p> <p>Abbeduto, Warren & Conners (2007)</p> <p>Buckley and Le Prevost (2002)</p> <p>Burgoyne (2020)</p> <p>O’Toole et al (2018) Cochrane review of parent-mediated interventions for Down syndrome</p> <p>Finestack & Rohwer (2021)</p>	<ul style="list-style-type: none"> ▪ DSE Interactive Communication and Play checklist and record sheets ▪ Intensive interaction. ▪ <i>DSE checklists</i> ▪ <i>DSE vocab lists</i> ▪ Early Years strategies handouts/training for settings and parents ▪ Parent child interaction approach. ▪ Verve child interaction approach. ▪ Routines based early intervention. ▪ Hanen It takes two to talk Programme – www.hanen.org • Key word signing systems Makaton/sign-a-long.



<p>Parents and educators need support from the SLT to develop a supportive communication environment and ensure they understand the speech and language needs of their child, and how speech and language develops.</p>	<p>Romski et al (2021) Warren et al (2020) Abbeduto et al. (2020) stress role of language environment</p>	
<p>Systematic approaches: Approaches which involve structured tasks – developed and modelled by SLT and carried out by parents/setting</p>	<p>Girolametto & Weitzman (2006) Warren et al. 2020 stress teaching responsive communication is not enough</p>	<ul style="list-style-type: none"> ▪ Derbyshire Language scheme/Language steps activities ▪ Verb and Noun photo resources. Black sheep Press, Pic toys. ▪ Teach me too programme resources ▪ DSE ‘See and Learn’ programme/resources ▪ DSE Vocab checklists
<p>‘Teaching’ (didactic) approach embedded in naturalistic play and interaction is effective for supporting children developing 1->2 word phrases</p>	<p>Clements-Baartman and Girolametto (1995) Warren et al. 2020</p>	<ul style="list-style-type: none"> ▪ As above
<p>Sign/visual representation of early vocabulary</p>	<p>Wilkinson & Finestack (2021) Romski et al (2021)</p>	<ul style="list-style-type: none"> ▪ See section on signing need for parent/carer training.
<p>Use of print e.g., Making personal books?</p>	<p>Finestack & Rohwer (2021)</p>	<ul style="list-style-type: none"> ▪ <i>See section on reading</i>



Specific approaches and interventions: It is important to have clear targets for 4 areas of work, speech, vocabulary, grammar and communication skills. Keep detailed records of progress. For vocabulary and grammar, have separate targets for comprehension and for production as comprehension in both domains is typically significantly ahead of production. For more detail please see the target section.

Intervention/ Approach	General notes/comments	Information and Resources
Vocabulary		
<p>Teach comprehension and expression of vocabulary with structured activities (as well as language in naturalistic settings)</p> <p>Choose words with consonants the child can already make, that are functional/meaningful/useful to the child.</p>	<p>Important link between productive vocabulary size and the development of expressive grammar - some of the grammar delay seen in children with Down syndrome is linked with delay in learning vocabulary. Galeote, M., Soto, P., Sebastián, E., Checa, E. & Sánchez-palacios, C. (2014).</p>	<ul style="list-style-type: none"> ▪ DSE Vocab checklists: ▪ DSE See and Learn Reading and Language resources See and Learn Language and Reading (note evidence base provided on website) ▪ Teach me too ▪ The Nuffield Early Language Intervention (NELI) is an evidence-based oral language intervention for children in nursery and reception who show weakness in their oral language skills. ▪ Routines based early intervention.
Making personal books	Evidence that seeing words as well as hearing them is a significant aid for many children with Down syndrome. Finestack & Rohwer (2021)	<ul style="list-style-type: none"> ▪ <i>See section on literacy</i>
Keep a record of words understood and words signed or spoken.		<ul style="list-style-type: none"> ▪ DSE checklists and record forms:
Grammar		
Teach two and three word constructions through play and	The development of grammar affects phonological development in children.	<ul style="list-style-type: none"> • Derbyshire Language Scheme/Language Steps • Pictoys



<p>encourage imitation by child (language immersion approach alone is not sufficient for children with Down syndrome – needs to be more targeted/structured).</p>	<p>Evidence shows older children/young adults with Down syndrome can improve grammar with intervention. Baxter (2018) Finestack & Rohwer (2021)</p> <p>Shape coding Tobin, L.M. & Ebbels, S.H. (2019)</p>	<ul style="list-style-type: none"> • Colourful Semantics • Black sheep press Language/Grammar resources • DSE See and Learn Reading and Language resources See and Learn Language and Reading (Phrases and Sentences kits - note evidence base provided on website) • Shape coding© https://www.moorhouseschool.co.uk/shape-coding • Teach me too
<p>Making personal books</p>	<p>Evidence that seeing words as well as hearing them is a significant aid for many children with Down syndrome. Mengoni et al (2013) Finestack & Rohwer (2021)</p>	<p><i>See section on literacy</i></p>
<p>Keep record of expressive and receptive grammar</p>		<ul style="list-style-type: none"> ▪ DSE checklists and record forms:
<p>Speech</p>		
<p>Listening and modelling environmental sounds.</p> <p>Discrimination activities could be introduced at an early age (before 2 years old). It has been suggested that speech work starts by 6 months or earlier because</p>		<p>Advice provided:</p> <ul style="list-style-type: none"> • How to develop a child’s listening skills. • Copying vocalisations • Symbolic noises • Environmental sounds, symbolic sounds and ‘sounds for meaning’, song recognition and completion



<p>of what we know about brain tuning to speech sounds from first weeks of life. Vihman (2017)</p>		<p>Information found below: https://www.downs-syndrome.org.uk/download-package/communication-series-pre-language-skills-for-babies-and-young-children/</p>
<p>Down Syndrome Education See and Learn sound packs. This places sounds in 3 groups in terms of development. Parents are encouraged to go through all sounds to support their child's listening skills. (Burgoyne, Buckley, Baxter, 2021)</p>	<p>Research can be found which highlights why children with Down syndrome struggle with speech. But there is limited research on interventions. Kent & Vorperian (2021)</p>	<p>DSE: See and Learn Speech See and Learn Speech (note evidence base provided on website)</p>
<p>Letters and sounds pack: Looks at sound discrimination and production in different phrases.</p>	<p>Integrated speech and phonological awareness intervention for pre-school children with Down syndrome. van Bysterveldt, Gillon, Foster-Cohen (2010)</p> <p>The findings of this study suggest an intervention approach that integrates speech, letter knowledge, and phonological awareness targets is effective.</p>	<ul style="list-style-type: none"> • Phonological awareness activities. • Speech discrimination tasks.
<p>Modelling letter sounds alongside photos or letters.</p>	<p>Buckley (2020) discusses going through common speech sounds with pictures during every day activities. E.g. sitting in the bath.</p> <p>Repetition is key. The more they hear a sound the more likely they are to be able to discriminate in words.</p>	<p>https://library.downs-syndrome.org/en-us/news-update/02/2/speech-language-therapy-down-syndrome/</p>



	<p>Buckley (2020) advised not to use signs when modelling sounds as children need to look at lip and face cues of adult.</p> <p>Using letters only would reduce the chance of the child associating a sound with a picture/ object. E.g. “oo” for moon. (Please see literacy section for more information)</p>	
Speech sound toy box: Modelling sounds with objects		
Core Vocabulary Approach	Dodd et al (2000)	http://integratedtreatmentservices.co.uk/wp-content/uploads/mediavault/2015/01/Core-Vocabulary.pdf
Nursery rhymes Early phonics programmes, e.g. Jolly Phonics and Letter Land Rhyming stories and poems		<p>Part of the “Pre-School: Small Group and Classroom Strategies” pack.</p> <p>Information found below: https://www.downs-syndrome.org.uk/speech-and-language-series/pre-school-small-group-and-classroom-strategies/?highlight=speech%20sound%20development</p>
Cycles Phonological Remediation Approach	Cycles approach to speech therapy is specifically designed and used for children who use many phonological processes in their speech, which can also be typical in children with Down Syndrome. (Rudolph and Wendt 2013)	
Interventions for children who have a hearing impairment?	These programmes must be specifically tailored to meet the needs of	See research cited earlier There may be a focus on more functional listening skills.



	children with additional hearing impairment.	
<p>Social/Functional Communication: The targets have to be focused on the child's individual needs and may be based on language functions.</p>		
<p>Can the child communicate a range of first meaning, in a differing contexts with a range of communication partners? Examples:</p> <p>Greetings; Existence; Disappearance; Recurrence; Possession; Rejection ; Non-existence; Location; Action; Agent; Object; Attribute</p> <p>Conversation skills; Requesting; Directing; Describing; Questioning; Giving information; Repairing misunderstandings</p>	<p>The focus is on the child or young person using the skills they have functionally.</p>	<p>Communication at the Heart of the School A Guide for Practitioners Working with Children with Learning Disabilities By Rachel Sawford and Ann Miles (2021)</p>
<p>Formal social skills packages.</p>		<ul style="list-style-type: none"> • Talkabout programme Alex Kelly • Sulp Social use of language programme Wendy Rinaldi • Black sheep press conversational programme and related resources.

Additional information is now provided on speech as this is an area frequently discussed in the literature.

Motor Speech Disorders

Wilson et al (2019) found a high prevalence of persistent speech delay (i.e. speech sound deletions and substitutions beyond 9 years of age) and motor speech disorders (childhood dysarthria and childhood apraxia of speech) in individuals with Down syndrome. Ataxic dysarthria was common, affecting voice quality and articulation of vowels and consonants. Therefore, the



authors concluded that it is important to consider motor speech during assessment and management of unclear speech in individuals with Down syndrome.

Oral-motor therapy

Catts (2021) describes Oro-motor therapy as the name given to non-speech oral motor exercises (NSOMEs) which are used in the expectation of eliciting and or improving speech sound. NSOMEs target the mechanisms which are used in speech production such as the tongue, lips, jaw, soft and hard palate and the larynx. Apraxia Kids (2021) report that the vast majority of the legitimate research shows no changes in speech sound productions because of non-speech oro-motor exercises. Despite the lack of evidence some therapists continue to offer this as an effective treatment for articulation difficulties in addition to dysphagia. Catts (2021) suggest that the lack of evidence for oro-motor therapy is a result of limitations during research e.g. small sample sizes, the shortage of randomised control trials and the lack of clarification given to the population groups which have been studied. Apraxia Kids (2021) believe oro-motor therapy is ineffective because of task specificity and that oro-motor exercises do not increase strength for speech as many clinicians claim.

The article by Apraxia Kids (2021) states that:

Task specificity is a reason why these exercises almost certainly will not affect speech. In order for there to be positive transfer of one behaviour (i.e., the exercise) to another behaviour (i.e., speaking) the task must be identical. But most oral motor exercises are NOT identical to the movements required for speech; no English speech sounds involve tongue wagging, whistling, tongue clicks or curls, etc. The relevancy of the task is important because context is crucial. Furthermore they claim that in the neurology literature, scientists have demonstrated how speech movement control is mediated at different nervous system locations than are non-speech movements. The training of irrelevant non-speech movements will not transfer to speaking because they are controlled by entirely different parts of the brain.

To read the full articles please visit: www.Cattsireland.com www.apraxia-kids.org

There is also an entry about NSOMEs in the What Works database:

<https://ican.org.uk/i-cans-talking-point/professionals/tct-resources/what-works-database/>

A useful parental leaflet:

[Parent-Friendly Information about Nonspeech Oral Motor Exercises \(apraxia-kids.org\)](http://www.apraxia-kids.org)

A decision regarding recommending this approach should be decided by the Speech and Language Therapist and the team they work with taking into account the evidence base.



Dysfluency:

Children and adults with Down syndrome often present with dysfluency, which may be characterised by any combination of stuttering, cluttering, dyspraxia and dysarthria (Bray 2014). Stuttering may include whole word or part word repetitions, prolongations and blocks, with “tense blocks” often being most prominent.

For direct therapy to be effective, the individual needs to be able to reflect on their speech behaviours, unhelpful and/or negative thoughts about speaking, and social-emotional factors related to dysfluency. For individuals with Down syndrome, this is likely to be challenging due to difficulties with language processing, auditory-verbal working memory, attention, cognition and phonological short-term memory. Hearing loss could also have an impact on perception of speech/ prosody etc.

Fluency shaping/ modification approaches have the potential to actually *increase* dysfluency in individuals with Down syndrome, due to the high cognitive load/ effort to attend to and memorise a new speech pattern. This could lead to avoidance and reduction in self-esteem for an individual with Down syndrome.

Bray’s study (2014) found that, although young people with Down syndrome were able to identify that communication was sometimes difficult, they tended to put the ‘blame’ on their listener (e.g. “they don’t listen to me really”) meaning their own self-esteem was not affected. The MPC found that teaching parents to praise their children with Down syndrome can be “one of the most effective tools of change”.

Recommendations:

- Communication Partner Training, since effective communication relies on both the speaker and the listener.
- Reduce linguistic demands – young people with Down syndrome have been found to have more fluent speech and use more body language/ gestures when interacting with peers compared to adults (i.e. when linguistic demands are lower).
- Focus on aspects of life that are fulfilling and positive for the individual with Down syndrome to maintain feelings of self-worth.
- Allow the individual with Down syndrome to work out their own strategies – some may spontaneously use strategies such as slowing down, speaking in syllabic manner, changing word when ‘stuck’ and asking someone else for help. Some of these strategies may be considered detrimental in traditional therapy approaches, but for individuals with Down syndrome they may be positive and more achievable than direct fluency shaping/ modification.
- Reading practice could also help – if the individual with Down syndrome can read, likely to read fluently and gain confidence and clarity.



Augmentative and Alternative Communication (AAC)

Every child who has Down syndrome is an individual, although language difficulties with understanding and using spoken words and sentences are common. This is often the case as children with Down syndrome have specific issues with processing the information they hear, whereas the information they see can be processed more easily.

Speech and Language Therapy often involves making spoken language more visual so that communication can be made easier for children with Down syndrome. This is most commonly done through teaching the child and those around them to use simple pictures and their hands to make signs, to visually support the key words of spoken messages. These methods, known as graphic symbols and manual signing, are examples of Augmentative and Alternative Communication, or AAC for short which refers to many different techniques that to 'add on' to spoken language to help get around communication difficulties. Using AAC will not stop a child from talking as speech is always modelled and encouraged alongside.

Although these methods cannot overcome language difficulties completely, research has found it is most helpful if such techniques are introduced early, are on-going in nature and used in combination (Wilkinson & Finestack, 2020). This is because children with Down syndrome can make the most of benefits early on in their development, can continue this when learning and using new words and can switch methods when needed. For example, if a communication partner was unfamiliar with manual sign or if the child struggled to remember or co-ordinate sign hand movements then graphic symbols could be used to help get their message across.

It must be stressed that research focuses on the value of signs more strongly as we do know children with Down syndrome use them to increase total expressive vocabulary before they can say the word. Research on this suggests gains to 24 month MA 48 months CA then spoken words take over.

Although Speech and Language Therapists are often involved in helping set up AAC intervention, parents and carers play the key role in helping their child to use AAC in everyday environments. Speech and Language Therapists should include practical advice around educating family members and training of those relevant in wider contexts such as educational and healthcare staff in AAC. It is also important to signpost parents, carers and professionals to relevant free or cost-effective resources, such as charity-led, library and online materials to support the maintenance of AAC for the child.



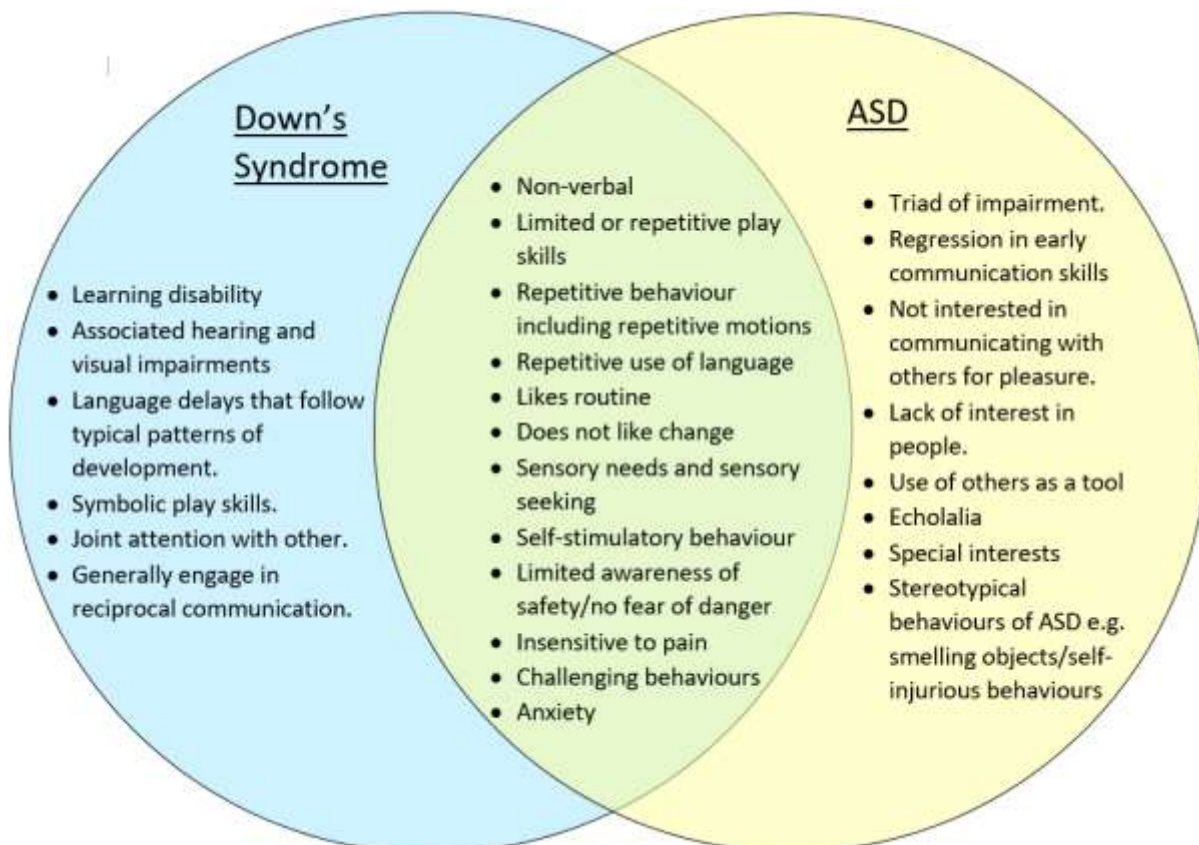
Down Syndrome and Autism:

It is often the case that children with the most severe needs often have a dual diagnosis of autism. It is believed that up to 18% (some research suggests up to 39%) of individuals with Down syndrome also have autism spectrum disorder.

“**Parents** often know in their hearts that something is amiss, but may be unaware that there may actually be a diagnosis to help them understand their child better. They may feel totally alone and overwhelmed as they observe other children with Down syndrome growing and developing according to expectations while their child exhibits behaviors more typically associated with autism - such as lack of communication, little eye contact, solitary play, fixation on objects, flapping or other repetitive behaviors, sleep problems, etc.

Healthcare providers may be reluctant to suggest a second diagnosis or may even be unaware that the two conditions can co-occur. If diagnosis is delayed, children may miss out on proven educational strategies such as early intervention and supplemental therapies. Early diagnosis and treatment are crucial, however it is never too late to seek an evaluation.” . <http://www.ds-asd-connection.org/what-we-know.html>

Below is a diagram that highlights traits frequently seen in children with Down syndrome, ASD and traits that may be observed in both conditions. This list is not exhaustive.





Bilingualism:

Research exploring the impact of bilingualism in children with Down Syndrome suggests that there is no detrimental effect of bilingualism on their language or literacy abilities. (Kay-Raining Bird, 2016) children with Down syndrome scored at least as well on all assessments as monolingual children with Down Syndrome.

In terms of clinical implications of this research, speech and language therapists should provide appropriate support for children with Down Syndrome in both languages to ensure they acquire each language to the best of their ability. This will avoid bilingual children with Down Syndrome being isolated from important life contexts shared with other family members. It will also ensure natural interact patterns between parents and children are not affected by parents choosing to interact with a child in a language they do not feel comfortable speaking in.

Literacy: The role of Speech and Language Therapy

For all children, there is a close and reciprocal relationship between language and literacy skills: oral language is the foundation upon which children learn to read and is essential for understanding print. In turn, literacy skills, and actively engaging in reading and writing activities, has benefits for oral language development. Speech and language therapists have a unique understanding of language, and practical skills of assessment and intervention planning and delivery. As such, speech and language therapists have an important role to play in supporting literacy development.

For children with Down syndrome, print is an important way to access language. As discussed above, individuals with Down syndrome find it difficult to process spoken language. Visual processing skills are relatively stronger which means that visual supports are very important for learning. Print is visual, tangible and lasting in ways which spoken language is not. Print can therefore be used to support spoken language learning and should be integrated into spoken language interventions. This is supported by experimental evidence which shows that seeing a word in print helps children with Down syndrome to learn new spoken words and grammatical rules.

Print-based activities can be used from an early age through to adulthood to support literacy and spoken language development. In the pre-school years, this includes learning letter sounds and playing sound games (phonological awareness), and modelling book reading and developing oral language through shared reading activities. In addition, programmes such as See and Learn Language and Reading (<https://www.seeandlearn.org/en-gb/language-and-reading/>), which support children to learn printed words and sentences, can be used from around the age of 3 as an explicit language teaching activity.

Once children start school they should be taught to read with the other children in their class. Because learning is more difficult for children with Down syndrome, reading instruction will need to be more explicit, intensive and for longer duration than for other children in school.



As they are for all children, phonological awareness and phonics skills are critical for reading in children with Down syndrome^{1,2}. These skills should form part of reading instruction (as in Reading and Language Intervention, designed specifically for children with Down syndrome; <https://www.down-syndrome.org/en-gb/resources/teaching/rli/>). Children will also need focused support for reading comprehension and for spelling and writing.

Personal books, featuring pictures and print, that are made with and for the individual also help build literacy into everyday learning and can be used at all stages of development.

Speech and language therapists can help to support literacy development in a number of ways:

1. *Provide direct, explicit instruction*

a) Recognize that many targets you are working on have a direct link to literacy

Speech and language therapists will already be working on many aspects of language (particularly phonology, vocabulary, and grammar) that underpin literacy development. Working on these targets in the spoken language domain can also benefit written language. For example, working on speech sounds (e.g. to support speech articulation) can have direct benefits for reading. Similarly, working on understanding pronouns (to support grammatical development) will have benefits for reading comprehension. It is important to recognize this!

b) Make the most of your interventions by building print into your intervention activities

Integrating print into your spoken language interventions will lead to greater benefits for spoken language development, and will also support literacy development. For example, use printed letters in speech sound work to encourage the child to learn the links between the sounds and the visual letter. Similarly, use printed word cards when working on grammar and sentences (e.g., if the target is he/she in spoken language; use printed word cards that can be matched to images and/or placed into sentences). All children, including those who are not yet reading independently, will benefit from these visual print-based supports. Model print-based activities for parents and educators so that they can use them as well.

2. *Advocate for high-quality literacy instruction for all*

Children with Down syndrome will not necessarily be automatically included in literacy learning opportunities, as others may not realize that children with Down syndrome can learn to read. Because of this, speech and language therapists have an important role to play in informing parents and educators of the importance of teaching children with Down syndrome to read and write. Include literacy skills in your assessments and target setting, and recommend literacy teaching and print-based activities. All children should have the opportunity to learn to read, including those who are more delayed.



3. *Assist others in supporting literacy development*

Provide parents and educators with evidence-based information and support relating to literacy development for individuals with Down syndrome, including:

- Sharing knowledge of the evidence for teaching children with Down syndrome to read through training and written guidance;
- Being aware of and informing others about available resources including See and Learn Language and Reading, Special iapps, and Reading and Language Intervention for children with Down syndrome;
- Explaining and modelling print-based teaching and intervention strategies/activities;
- Assessing literacy skills and collaborating with others to set appropriate targets for literacy and develop individualized support.

Target setting

All experts identify the need to have separate targets for the four components of speech and language skills - communication, vocabulary, grammar and speech work, for each child.

Please find at the end of this document a target setting template, which also includes opportunities to add ongoing strategies, strengths and challenges

Updates and feedback

We hope to continue to develop and evolve this Toolkit and welcome feedback and contributions.

Please visit Down Syndrome Education International's web site to get in touch and offer your feedback, and to learn about future updates to this Toolkit.

<https://www.down-syndrome.org/resources/slt-toolkit>



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Further information

On medical and health issues

<https://www.dsmig.org.uk/information-resources/by-topic/>

Further reading on language and literacy

Burgoyne, K. (2020). Down's syndrome: Language Development and Intervention. *The Bulletin*, Royal College of Speech and Language Therapists (RCSLT), August.

Burgoyne, K. (2011). Reading the evidence: What does research tell us about developing the reading skills of children with Down syndrome? *Special Educational Needs*, January.

Burgoyne, K., Baxter, R. & Buckley, S. (2014). Developing the reading skills of children with Down syndrome. In R. Faragher & B. Clarke (Eds.), *Educating Learners with Down syndrome*. Routledge Education.

Language Unlocks Reading: Supporting Early Language and Reading for Every Child. National Literacy Trust.

Resources to support speech, language and literacy in children with Down syndrome

See & Learn Language and Reading (<https://www.seeandlearn.org/en-gb/>)

Special iapps (<https://www.specialiapps.org/en>)

Reading and Language Intervention for children with Down syndrome (<https://www.down-syndrome.org/en-gb/resources/teaching/rli/>)

In depth training courses for Speech and Language Therapists

Down Syndrome Education International online course (Sue Buckley) [Improving speech and language development for children and young people with Down syndrome \(down-syndrome.org\)](https://www.down-syndrome.org)

Symbol Connect courses [DOWN SYNDROME \(SALT\) – Symbol \(symbolconnect.co.uk\)](https://www.symbolconnect.co.uk)



Case history example:

CONFIDENTIAL PATIENT INFORMATION.

Case History including considerations for children with Down Syndrome.

Ideally the case history form would be sent to the parent/carers ahead of time so they could prepare and complete what they can themselves. If necessary the parent could also be asked to complete vocabulary checklists and/or send the SLT any additional information e.g., audiology/vision/paediatrician reports.

Before embarking on the case history session please explain to the parents/carers the aims of the session and why a case history is important.

Child's Name:	
Child's DOB:	
NHS Number:	

Interview conducted by:	
Date of case history:	
Parent/Carer's name and relationship to child:	1) 2)
Contact Number(s): Which is the preferred?	Mobile: Home: Email:
Address (full time?):	
GP and Address:	
Who has Parental Responsibility?	
Information from referral: Date and who referred:	



Child has been referred by the referrer with concerns:	
<u>Others present at the interview:</u>	

The questions detailed below are separated into the four sections, which are described in Bray, Ross & Todd. (2006) Speech and Language: Clinical Process and Practice text.

<p><u>Physiological Medical Factors.</u> Medical Information. Hearing and Vision. Motor Control. Family History. Developmental Milestones.</p>	<p><u>Social/emotional/behavioural factors.</u> Awareness of strengths and weaknesses Behavioural characteristics Relationships Emotional Stability Social Skills</p>
<p><u>Environmental Factors.</u> Family Circumstances Social / work information Pressure from others Demands of environment Reaction of others.</p>	<p><u>Cognitive/developmental factors.</u> Speech language Play Attention Memory Learning ability and problem solving Literacy</p>

Environmental Factors.

Family Circumstances:
 Number of children in the family:
 Number of people living in the family home:
 Is your child growing up in a home that uses a language in addition to English?
 If yes answer the questions below:
 Languages spoken at home (inc. signs):

- Which language is spoken mostly at home?
- Do you speak another language with your child?



<ul style="list-style-type: none"> • How long has your child been hearing English and where? • Which language do they find it easier to understand? • If your child has started talking which language do they choose to speak in? 			
Name of sibling:	Gender	DOB:	Any SLT or education needs?
<u>1)</u>			
<u>2)</u>			
<u>3)</u>			
<u>4)</u>			
Notes:			
Can you let us know a bit about your family? What do you like to do together?			
What additional pressures do you have? Demands of the environment?			
Reactions of others in the family?			

Physiological and medical Factors.

Other diagnosis: Suspected? Physical implications, e.g. heart conditions:



Medication: affects?
Epilepsy:
Hearing: (audiology).
Vision:
Illnesses / operations: e.g. any up and coming surgeries scheduled?
Associated implications / impact of medical needs on child and family? Will this impact SLT involvement / priority?
Do you have concerns about your child's eating, drinking and swallowing (EDS)? General comments here, but if necessary the therapist will use another more specific EDS case history.
How was your pregnancy and birth? Full term/premature?
Describe your child's general physical development e.g. sitting, crawling, and walking. The age they achieved these milestones?



Does your child sleep well?

MDT: other professionals involved in your child's care?

- Community Paediatrician
- Acute Paediatrician/ consultants?
- Physiotherapy
- Occupational therapy
- Health visitor
- Portage
- Dietician
- Down Syndrome advisory services (e.g., early intervention groups; school support)
- Other

Cognitive/developmental factors.

Methods of communication: How does your child communicate with you? What does he/she generally communicate about?

e.g. words, signs, movements, vocalisation, pointing.

e.g. to make requests, to tell you what they like/dislike, to comment on what they see.



Areas of strength relating to your child's speech, language and communication? E.g. social communication?

Can you describe when your child used their first:

Signs/gesture:

Spoken words:

Short phrases:

Regression: Have they ever 'lost' words?

Parent's views of expression and comprehension:

Expression: How does your child communicate?

-gestures, pointing, words, signs, photographs, symbols.

-length of sentences

-The types of words/signs used.



Comprehension: How does your child understand what is happening to them?

- Do they understand familiar routines?
- Objects as part of an activity?
- Do they understand verbal language, gestures, visuals (photographs/symbols), signs?
- What types of words do they understand?

Speech:

- Concerns with speech sounds?
- Hear the difference between sounds?
- Produce the difference?
- Consider differences in oral structure and function?

Vocabulary:

- Listening and naming?
- DSE Vocab Checklists?
- DSE Interactive communication and play checklist?



Pragmatics:

Functions of communication. Can your child greet, requesting, commenting, disappearance etc.

Literacy/reading skills:

Attention and Listening skills:

Play Skills:

Exploratory play? Relational play? Simple Pretend play?

Cognition: Has your child seen an educational psychologist?

Professional to consider further assessment for processing time?

Auditory Memory? Phonological memory skills vs possible strengths in visuo-spatial memory.

Non word repetition.



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Social/emotional/behavioural factors.

Can you comment on your child's social skills?

Eye contact, social routines, keenness to communicate with others, making friends, turn taking skills, preference to familiar adults/ children. Awareness of other in environment, initiating interactions, asking and answering questions

Does your child have any additional sensory needs?

How does your child play with other children?

How would you describe your child's behaviour?

Are there any strategies that you find helpful?

Do speech and language difficulties affect your child's participation in school and the community?

E.g., accessing the curriculum, socialising with friends and family.... If so, how



Does your child have any concerns about their speech and language? E.g., does your child get frustrated?

Has your child had SLT input before? When? Have any other systems been introduced e.g. Signing –Signalong or Makaton?
Have you received input from Down Syndrome Association/ charity groups? If so what advice/support has been provided?
What have you tried in order to help your child with their talking? Was it useful/ did it help?

What would you like to achieve from Speech and Language Therapy input? What are your priorities?
Is there anything else you would like us to know?



**Parental Consent to share this information with other members of the MDT if required?
(Please tick).**

I do NOT give my consent to share information with other members of the MDT surrounding my child if required.

I give my consent to share information with other members of the MDT surrounding my child if required.

Signed

Printed Name

Date.....

Clinician(s):

Signed

Printed Name

Title.....

Date.....

Signed

Title.....

Printed Name

Date.....

Additional Notes:



Target setting formulation

Intervention Planning Document:			
Name		NHS No.	
DOB		Therapist	
Strengths		Challenges	
Target setting:			
• Communication		• Vocabulary	
• Grammar		• Speech work	
Ongoing Strategies			Date Completed:
			To be reviewed:



Intervention Planning Guidance			
Name		NHS No.	
DOB		Therapist	
Strengths		Challenges	
What are the child's strength e.g. visual learners, social communication.		This maybe challenges in the environment e.g. not all staff have accessed signing course.	
Target setting:			
<p>Communication (Functional communication)</p> <p>pre-linguistic skills (e.g. eye-contact, joint attention, non-verbal communication, gesture use), total communication, turn taking, sharing, co-operation, attention and listening skills, requesting, initiating, use of context, maintaining topic, following conversational rules, pragmatic skills, understanding jokes and idioms, making and maintaining friendships.</p>		<p>Vocabulary</p> <p>Receptive vocabulary and language – understanding of single vocabulary words covering a range of syntactic categories including nouns, verbs, adjectives, pronouns, prepositions, time and quantity. In line with the development of the child and their vocabulary, language targets would be incorporated into the session and include; following longer key word phrases using a variety of constructions (e.g. action-object, object-possession, agent-action-object), understanding grammatical markers (e.g. 'ed' past tense marker, plural 's').</p>	
<p>Grammar</p> <p>Expressive vocabulary and grammar - as receptive targets are achieved, expressive targets following this same pattern of development would be covered; focussing on single vocabulary word production (including spoken words and sign) covering a range of syntactic categories. Expressive language targets would be incorporated into the session including multi word utterances and the use of more complex sentence structures including the use of grammatical markers (e.g. 'ed' past tense marker, plural 's').</p>		<p>Speech work</p> <p>listening and discrimination skills, production of symbolic sounds, single sounds, sound combinations, use of sounds in words, connected speech, syllable marking, intonation, rate and stress, fluency, intelligibility and clarity.</p>	
Ongoing Strategies			Date Completed:
Key word signing, use of visuals, chunking of language, recasting etc.			To be reviewed: