

Supporting Children with Down Syndrome in the Early Years



Supporting Children with Down Syndrome Guidance

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Overview

Down syndrome - also known as Down's syndrome - is the most common form of learning disability. Down syndrome is a condition in which a person has an extra chromosome. Chromosomes are small "packages" of genes in the body. They determine how a baby's body forms and functions as it grows during pregnancy and after birth. Typically, a baby is born with 46 chromosomes. Babies with Down syndrome have an extra copy of one of these chromosomes, chromosome 21. A medical term for having an extra copy of a chromosome is 'trisomy.' Down syndrome is also referred to as Trisomy 21. This extra copy changes how the baby's body and brain develop, which can cause both mental and physical challenges for the baby.

There are three types of Down syndrome. People often cannot tell the difference between each type without looking at the chromosomes because the physical features and behaviours are similar:

- **Trisomy 21:** About 95% of people with Down syndrome have Trisomy 21. With this type of Down syndrome, each cell in the body has 3 separate copies of chromosome 21 instead of the usual 2 copies.
- **Translocation Down syndrome:** This type accounts for a small percentage of people with Down syndrome (about 3%). This occurs when an extra part or a whole extra chromosome 21 is present, but it is attached or "trans-located" to a different chromosome rather than being a separate chromosome 21.
- **Mosaic Down syndrome:** This type affects about 2% of the people with Down syndrome. Mosaic means mixture or combination. For children with mosaic Down syndrome, some of their cells have 3 copies of chromosome 21, but other cells have the typical two copies of chromosome 21.

Children with mosaic Down syndrome may have the same features as other children with Down syndrome. However, they may have fewer features of the condition due to the presence of some (or many) cells with a typical number of chromosomes.

Even though people with Down syndrome might act and look similar, each person has different abilities. People with Down syndrome usually have an IQ (a measure of intelligence) in the mildly-to-moderately low range and are slower to speak than other children.

People with Down syndrome are living longer. The approximate life span now is 60 to 70 years.

Some common physical features of Down syndrome include:

- A flattened face, especially the bridge of the nose
- Almond-shaped eyes that slant up
- A short neck
- Small ears
- A tongue that tends to stick out of the mouth
- Tiny white spots on the iris (coloured part) of the eye
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Small little/pinkie fingers that sometimes curve toward the thumb
- Poor muscle tone or loose joints
- Shorter in height as children and adults.

Developmental Milestones Overview

Taken from the 2020 Down Syndrome Personal Child Health Record (Red book)

<https://www.healthforallchildren.com/wp-content/uploads/2020/02/A5-Downs-charts.pdf>

There is no such thing as a typical child who has Down syndrome. Children who have Down syndrome are as different from each other as are all children. However, their development is generally slower than most children. The charts which follow give the usual developmental progress

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about moving



<u>Activity</u>	<u>Children who have Down syndrome</u>		<u>Typical Children</u>	
	Average age	Range	Average age	Range
Holds head steady when sitting	5 months	3-5 months	3 months	1 - 4 months
Rolls over	8 months	4-12 months	5 months	2-10 months
Sits alone	9 months	6-16 months	7 months	5-9 months
Stands alone	18 months	12-38 months	11 months	9-16 months
Walks alone	23 months	13-48 months	12 months	9-17 months

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about people

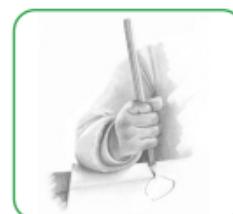


Activity	Children who have Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Smiles when talked to	2 months	1.5-4 months	1 month	1-2 months
Plays pat-a-cake or peek-a-boo	11 months	9-16 months	8 months	5-13 months
Drinks from an ordinary cup	20 months	12-30 months	12 months	9-17 months
Dry by day	36 months	18-50 months+	24 months	14-36 months
Bowel control	36 months	20-60 months+	24 months	16-48 months

of children who have Down syndrome. By understanding what is usual for a child who has Down syndrome you will be able to recognise any additional issues at an early stage.

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about hands



Activity	Children who have Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Follows objects with eyes	3 months	1.5-6 months	1.5 months	1-3 months
Reaches out and grasps objects	6 months	4-11 months	4 months	2-6 months
Passes objects hand to hand	8 months	6-12 months	5.5 months	4-8 months
Builds a tower of 2 cubes	30 months	14-32 months	15 months	10-19 months
Copies a circle	48 months	36-60 months+	30 months	24-40 months

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about words



Activity	Children who have Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Responds to sounds	1 month	0.5-1.5 months	0 month	0-1 month
Babbles "Da-da" and "Ma-ma"	7 months	4-8 months	4 months	2-6 months
Responds to simple instructions	16 months	12-24 months	10 months	6-14 months
First words spoken with meaning	18 months	13-36 months	14 months	10-23 months
2-word phrases	30 months	18-60 months+	20 months	15-30 months

Developmental Journal for Babies and Children with Down Syndrome

The Developmental Journal for babies and children with Down syndrome is a tool to help track and understand development of the child and to share that information with other people. It:

- Helps you record and celebrate change, achievements and progress in the early years.
- Helps you understand the significance of what the child is doing now, what they will do next and how you can support their progress
- Provides an on-going record of the child's achievements, progress and development as they learn to do new things
- Recognises the important information about the child that you have and makes it easier for you to share that information with other people
- Helps professionals work in partnership with families by providing a shared basis for discussion
- Supports effective early intervention services by improving everyone's understanding of the developmental processes involved.

The journal is available at

<https://councilfordisabledchildren.org.uk/resources/all-resources/filter/schools-colleges-and-fe/downs-syndrome-development-journal-early>

Health Issues

Children who have Down syndrome have health issues that can affect any child. However, some health issues occur more often in children who have Down syndrome. It can sometimes be hard to recognise the health problems and therefore it is recommended to have some extra health checks to identify and manage the condition as soon as possible.

Heart

About half of all children who have Down syndrome are born with a heart problem. It is important to identify these in the first 2 months, as early treatment may be needed. It is recommended that all children must have a thorough heart examination, including an echocardiogram, by six weeks of age to enable prompt treatment.

Blood

Children who have Down syndrome should have their blood count and blood film checked within the first three days of birth, to identify any serious blood disorders. A few may need treatment or on-going checks.

Vision and Hearing

Children who have Down syndrome are more prone to have difficulties with their hearing and vision. It is important to identify these early on, so that appropriate help can be given to minimise the effect of a hearing or visual impairment on the child's development.

Up to 50-70% of people with Down syndrome will experience impaired hearing at some point in their life. Hearing losses may be conductive, sensorineural or mixed in nature, and may be temporary or permanent. The patterns of hearing loss presenting in Down syndrome change throughout life, with otitis media with effusion (glue ear) the most common cause in childhood, and sensorineural deafness becoming more prevalent with age.

Otitis media with effusion (OME or glue ear) affects up to 35% of children with Down syndrome at birth and 93% at 1 year old, reducing to 68% and 38% by the ages of 5 and 8 respectively. There is a higher incidence of ossicular abnormalities in Down syndrome which may present with a conductive hearing loss. The incidence of sensorineural hearing loss identified at newborn hearing screening in children with Down syndrome is higher than in the general population at 4-6%.

At all ages, people with Down syndrome have narrow ear canals which predispose to accumulation of wax. This may affect impedance testing and hearing

NICE Guidelines (2008) recommend hearing aids as the first-line treatment for hearing loss associated with glue ear in children with Down syndrome. For about 1 in 5 children without Down syndrome who have had grommets, glue ear comes back again. This is much more likely in children with Down syndrome but, because the glue is more sticky, the grommet itself often becomes blocked and the improvement in hearing may be short-lived. This may mean that further grommets need to be fitted.

It is possible to put grommets in about three times. However, repeated grommet operations are not recommended as every time one is put in, the eardrum is punctured and when it falls out a scar is left. Because of this, some Ear, Nose and Throat (ENT) doctors recommend hearing aids as the preferred treatment for glue ear in children with Down syndrome.

All children with Down syndrome should have new-born hearing screening followed by targeted hearing assessments, initially at 6 to 10 months and then six monthly till the age of two and to continue at least annually throughout school-age years.

Thyroid

The thyroid gland is more frequently underactive in children who have Down syndrome. The symptoms of thyroid disorders can be difficult to spot. An underactive thyroid can affect a child's growth, learning and general health. Treatment is simple and effective. It is recommended that the child has an annual blood test to identify the condition early on.

Constipation

Constipation is common in children who have Down syndrome. In most cases it is not due to any underlying bowel condition and can be managed as it would be in any child. If constipation is present since birth, or is severe and persists despite simple measures, then parents should discuss their concerns with their doctor.

Toilet training

Children who have Down syndrome are usually toilet trained by the age of 3.5 - 4 years old. If the child is still in nappies at 4 years old, then they need to be seen by a medical specialist to make sure that their bladder and kidneys are working properly.

Coeliac Disease

Although Coeliac disease (sensitivity to a protein in wheat, called gluten) can occur more frequently in children who have Down syndrome, routine screening is currently not recommended. Symptoms of Coeliac disease include bowel problems, tiredness or a change in behaviour. There should be a low threshold for checking for Coeliac disease and, if the child has symptoms parents should seek advice from their doctor.

Breathing

Babies often have nasal congestion. Saline drops and nasal suction can sometimes help. Sleep apnoea occurs more commonly in children who have Down syndrome. Symptoms of sleep apnoea include gasping momentarily stopping to breathe or snoring whilst sleeping. It is recommended for all children who have Down syndrome to have their oxygen levels checked overnight, whilst asleep, at around the age of six months and then once a year until the age of 5. This is an easy procedure which can be done at home. This is to ensure that their breathing pattern and oxygen levels are normal.

Infections

Children who have Down syndrome are more vulnerable to chest infections and other serious infections. They may not show the same signs and symptoms as other children. If you are worried that the child may have a serious infection, seek urgent medical advice so that a serious illness such as sepsis or pneumonia can be identified and treated early. Children should receive all childhood immunisations, possibly including the flu vaccine every year and Pneumovax II at 2 years of age.

Teeth

Baby and permanent teeth often come late and in a different order compared to other children. Gum and teeth infections can occur more commonly and can be serious. Children should brush their teeth twice a day and visit a dentist every six months.

Physical Development

Many children with Down Syndrome have a degree of floppiness of their muscles (hypotonia) and this affects each child to a different degree. Low muscle tone, as well as reduced strength and endurance, make it hard to learn gross motor skills.

Children with Down Syndrome also have increased flexibility in their joints (hypermobility), and you may first notice this in the child's hips as their knees fall to the sides when they are lying on their back.

Some children may have flat feet. Children with Down Syndrome also have short arms and legs relative to the length of their trunk. This makes it harder to prop themselves up when they are learning to sit, or more difficult to climb on furniture.

Physical activity will help to promote a child's gross motor skills and increase their muscle strength. They will need lots of stimulation through handling and play. A physiotherapist can provide activities to carry out to help the child with their gross motor skills. Repetition and practice will help a child to increase their muscle strength and ability.

Arthritis

Children who have Down syndrome are more commonly affected by arthritis. They may not easily express the pain that they are experiencing. A change in a child's ability to perform daily living activities, e.g. in their handwriting or walking abilities may be an indication of early onset arthritis. Parents should seek advice from their doctor if the child is experiencing any of these difficulties or if you are concerned.

Neck Instability

Neck instability can occur at any age in children who have Down syndrome and though this is rare, it can be very serious. Routine neck X-ray screening does not help to detect the problem. Children with neck instability, usually have warning symptoms e.g. neck pain, holding their head or neck in an odd position or a change in their motor skills or continence. If a child develops any of these symptoms, an urgent medical assessment should be sought.

Immunisations

Children who have Down syndrome may be particularly susceptible to infections and it is very important they have the same immunisations as everyone. For some children, particularly those with heart problems, additional immunisations may be recommended, for instance to protect against seasonal flu and some respiratory infections.

Health Check Schedule

DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

	Birth - 6 weeks	Special checks under 2 years	Preschool checks	School age
Thyroid blood tests	Newborn routine heel prick - blood spot test	Age 4-6 months and then every year from the age of 1 year or more often if clinically indicated: Venous thyroid blood test including thyroid antibodies <u>or</u> Fingerprick TSH test		
Eye checks	Newborn routine check including congenital cataract check	Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or short sight	Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity	Repeat vision test every 2 years , or more frequently if recommended by optometrist or ophthalmologist or if concerns
	Visual behaviour to be monitored at every review particularly in first year			
Hearing checks	Universal newborn hearing screen	Full audiological review by 10 months including hearing test impedance check	Annual audiological review or more frequently and if indicated 2 yearly audiological review or more frequently if recommended	
Growth monitoring	Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts		Height and weight should be checked and plotted on Down syndrome growth charts at least annually (BMI checked if concern regarding overweight)	
Heart checks	By age 6 weeks , formal heart assessment including Echocardiogram	At all ages low threshold for reviewing heart status if signs or symptoms develop		From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease
Breathing checks	Enquire at every review for uneven breathing during sleep and poor quality sleep. Screen with an overnight pulse oximetry once in infancy and yearly until the age of 5, or at any age if there are symptoms or concerns. Low threshold for detailed sleep studies if symptoms persist, despite normal tests			
Blood checks	Within the first three days of life, full blood count and blood film to check for a serious blood disorder	If blood film is abnormal treatment or monitoring may be required		

Feeding

Many babies who have Down syndrome feed just as well as other babies. Some babies may have feeding difficulties, in the first few weeks, especially if they have additional health issues. If a parent had decided to breast feed the baby before they were born, they do not need to change their mind just because their child has Down syndrome. Most mothers who want to, do breast feed their babies successfully although it may take longer to establish. Mothers may find it helpful to express breast milk for a time and use this to feed the baby. They can go back to breast feeding, if and when the baby is able to manage to breast feed. The child's health visitor or a breast-feeding expert will be able to advise parents about these issues. Breast feeding support groups such as La Leche League and the National Childbirth Trust provide useful information, some of it specifically about feeding babies who have Down syndrome.

The most common feeding issues are:

- The baby falls asleep soon after starting feeding so does not take enough.
- The baby may have a weak suck.
- The baby's coordination of sucking, breathing and swallowing has not yet matured so they get tired and distressed and again they end up not getting enough milk.

These issues usually get better after the first few weeks but understandably can be very worrying for parents at the time. If the baby is experiencing these issues, feeding little and often can help, until feeding settles down to normal. Parents may even need to wake the baby up at night to feed.

Some children may have issues with feeding at later stages of development, for example when moving on to solids. If this happens the child's health visitor will be able to advise, and the child may need more specialist help from a Speech & Language Therapist.

Four Broad Areas of Need

Communication & Interaction

Babies with Down syndrome are keen to communicate, but may find it more difficult to express themselves using sound, because of the shape and size of their mouth and tongue. It is important to talk with the baby right from the start of life because they like to watch your face and listen to you. They are likely to pay particular attention to 'baby-talk', that is, when you talk in short simple sentences, using a lively tone of voice and lots of facial expression and gesture. As well as repeating what you say, it is important to allow enough time and space for the baby to join in. It is good to talk to the baby about what they are doing and might be thinking – it helps the two of you develop your relationship and encourages them to communicate.

When we are learning language, we generally see an object and hear a sound string and then we match the two together and store it (and its meaning) in our brains. For example, we hold up an object, let's say a big red ball and then say to the child in a squeaky, friendly voice "ball". The child then matches the two things together, red, shiny object and sounds b, a, l, l and attributes meaning to it. This process is dependent on the ability to hear sounds, remember them temporarily and then link together to form meaning. We refer to this as the phonological loop. For all children, the phonological loop is thought to play a critical role in learning a spoken language, but we know that children with Down syndrome often have poor auditory short-term memory and auditory processing can be an area of weakness too. So, the ability to remember the sound they have heard and process it is not an area of strength and it can therefore be difficult for them to acquire expressive language.

One of the areas of communication difficulty that most people are familiar with in people with Down Syndrome is speech intelligibility. This is often one of the most difficult areas for people with Down syndrome at all ages. Speech is highly complex. It involves coordinating breathing (respiration), voice (phonation), and the production of speech sounds (articulation).

However, while auditory short-term memory and auditory processing can be areas of weakness, children with Down syndrome often have excellent visual memory. Seeing words and images associated with sounds can help speech and language develop. So, when they are learning language, it is vitally important that there is a strong visual element to it. Offering pictures, signs and symbols at the same time as you say a word can help them learn.

Key facts:

- Children with Down syndrome often have a speech and language impairment and are often late starting to talk.
- They also follow a pattern of language development which differs from typical development.
- Most children with Down syndrome develop spoken language skills more slowly than their non-verbal mental abilities. They have therefore been described as having a specific speech and language delay.
- However, they are often keen communicators - they can use and understand sign, gesture and body language to support and develop their communication skills.
- Vocabulary is learned slowly & steadily – especially nouns.
- Expressive – Receptive gap – children with Down Syndrome can understand more than they can say.
- Early grammar is delayed and learned slowly & is paced by the size of the child's vocabulary - need to acquire a vocabulary of approx. 300 words before developing and applying grammar).
- Will often speak using key words and leaving out the connecting words - "telegraphic" speech e.g. "sit chair".
- Problems with articulation may result in the child being unwilling to speak in longer sentences and they may self-limit as a result.
- Difficulties understanding the specific language of the curriculum.
- Often good social interaction skills.
- Strong visual skills.
- Speech and Language can be compromised by:
 - hearing difficulties,
 - difficulties with Auditory attention & Auditory memory - listening, staying focused, ability to process & retain information
 - Difficulties with auditory discrimination.
- Research shows children with Down Syndrome do not learn words easily from speech input alone - all benefit from up to 100 signs with spoken word.
- Children have larger vocabularies when in sign supported programmes.
- 25% of 4-year-olds still need to use sign as major mode of communication and should be taught new signs alongside speech and reading.

Strategies to support:

- Make use of child's strong visual skills & support all language visually – gesture and sign, pictures, print, drawings & symbols and concrete objects.
- Surround by good language models.
- Use simple, direct language. Clear, concise instructions.
- Phrase questions which require more than a yes/no.
- Give extra time for child to process and organise response.
- Work on speech sounds - accurate production /articulation skills.
- Practise sentence structure.
- Use 'carrier phrases' to help develop sentences: I like....I want....
- Teach prepositions through games.
- Teach grammar through reading.
- Develop memory skills e.g. use routine songs; counting games; things you say as you change, dress, feed or wash the child. The more repetitive you are the more it all makes sense.

- Play with sound making toys but don't let sound making toys mask out your voice.
- Pause when you are about to say something so the child is ready to listen.
- Always be alert to sounds around and draw the child's attention to them.
- Draw the child's attention to things of interest- these give you a reason to talk. Check when you are talking about what you are seeing, that the child is looking at the same things.
- Talk about what you are doing and react to the child's reactions.
- Play tickle games.
- Repetitive peek-a-boo games.
- Hiding and finding games.
- Encourage turn taking. Offer turns in your conversation- waiting for the child to take a turn. Give the child plenty of time to reply.
- Give the child something to do or hold in a game. Encourage opportunities for turn-taking. Action rhymes help the child to be involved.
- Use anticipation games so the child learns to expect something is going to happen like a tickle, a cuddle, a boo, a snap or a roar.
- Sharing books and the same ones again and again – you will be sharing the same focus and so it is clear about what you are saying. Continued sharing will allow the same language to be used, add your own ideas and repetitions. Help the child to anticipate and wait for the sound and action or participate in the expected action.

Cognition & Learning

Children are not just developmentally delayed – they have a specific learning profile with implications for differentiation/adaptations.

Key facts:

- Children with Downs syndrome have learning difficulties, but these can vary from mild to severe.
- They are often good visual learners & poor auditory learners – learning from listening is VERY hard for them.
- They often have excellent visual memory.
- They are often excellent readers.
- Most children manage well in mainstream schools given additional support and adapted activities where appropriate.
- Children often have the ability and desire to learn from peers - to interact, imitate & take their cue from them. Most children benefit from being with typically developing peer groups who provide models for speech and language and social skills.
- Children with more significant difficulties may benefit from attending a special school
- Progress for children with Down syndrome does not decline as they get older, nor do they plateau in their development. However, they develop more slowly than their peers, arriving at each stage of development at a later age and staying there for longer.

Strategies to support:

- When learning it is vitally important that there is a strong visual element to it. Differentiation/adaptations must be child-centred & visual, as practical as possible & use familiar & meaningful language.
- Offering pictures, signs and symbols at the same time as you say a word.

- Children with Down syndrome usually love to look at books and it's a great way to teach them, as they remember things that they see and hear more easily than things that they just hear, and to build attention and focus.
- Reading and the use of computer programmes focusing on language skills.
- Tracing their fingers around written letters/words when you introduce them to a new word.
- Lots of opportunities for repetition and over-learning.
- Develop small sequences of actions to help children learn e.g. the order in which to get dressed.

Social, Emotional and Mental Health

There are no behaviour problems unique to children with Down syndrome. However, much of their behaviour will be related to their level of development and not to their chronological age. So, when problems occur, they are generally similar to those seen in typically developing children of a younger age.

In addition, many children with Down syndrome have to cope with more difficulties than many of their peers. Much of what they are expected to do in their everyday lives will be much harder to accomplish due to problems with their speech and language, auditory short-term memory, motor co-ordination, shorter concentration span, and learning difficulties. Children with Down syndrome can also take longer to "learn the rules" and understand changes in their environment. As a result, they may feel more insecure and anxious and need additional, specific help.

Their thresholds for problem behaviours may therefore be lower than in typically developing children, i.e. they are likely to become frustrated or anxious more easily. So, having Down syndrome does not lead inevitably to behavioural problems; but the nature of their learning difficulties makes such children more vulnerable to the development of such problems.

One aspect of problem behaviour is the use of avoidance strategies such as frequent visits to the toilet, refusing to line up after break, hiding under the table or losing their glasses. Many children with Down syndrome tend to adopt these, thus undermining their progress. Some children use social skills and attention seeking behaviours to avoid tasks - refusing, pretending to be less capable than they really are or distracting the adult by talking about their holiday or their dog.

Key facts:

- Often at the root of inappropriate behaviour are the increasing cognitive demands facing the child with Down syndrome. The child may well be finding it difficult to cope with current activities and goals.
- Children with Down syndrome are usually very friendly sociable children. They enjoy being with their peers.
- They have good social interactive skills and use gestures and facial expressions effectively to help themselves communicate.
- Children often have the ability and desire to learn from peers - to interact, imitate & take their cue from them. Most children benefit from being with typically developing peer groups who provide models for speech and language and social skills.
- People with Down syndrome are capable of forming all types of relationships be it friendship, love or a dislike of someone.

- Children with Down Syndrome can display avoidance behaviours, trouble controlling impulses and difficulty managing frustration.
- Many children with Down syndrome are social and affectionate. But often, they may not know how to play efficiently with peers, or peers may 'baby' them. This can be very upsetting to the child with Down syndrome.

Strategies to support:

- Be consistent in routines, rules and expectations so the child knows what is expected. Teach rules explicitly. Ensure they are understood and reinforce them visually.
- Behaviour is a communication- what is the child communicating?
- Children with Down syndrome are often sensitive to failure. Recognition of this and a corresponding look at the child's curriculum to ensure that it is suitably differentiated/adapted are therefore critical in responding to behaviour problems.
- Ensure that the children's developmental, not chronological, age is taken into account, together with their level of oral understanding.
- Distinguish "can't do" from "won't do".
- Use short, clear instructions and clear body language for reinforcement: overlong explanations and excessively complex reasoning are not appropriate.
- Encourage positive behaviour by using visual reinforcement. Use a photo book with pictures of the child behaving appropriately in different situations, e.g. tidying up, sitting nicely on the carpet or lining up, together with short sentence descriptors.
- Ensure the child is working with peers who are acting as good role models.
- Give plenty of praise and encouragement. Be clear and specific when praising.
- Reinforce the desired behaviour immediately with visual, oral or tangible rewards.
- Make sure they are involved in whatever is going on. Let them hold the big book, hold up puppets from the story or act it out.
- Ensure that all staff are aware of and are consistent in the delivery of the strategies to be employed.
- Try distraction rather than confrontation.
- Be consistent. Make sure everyone responds to the behaviour in the same way.
- Ignore attention-seeking behaviour within reasonable limits: it is aimed to distract. Do not respond to attention-seeking behaviour by giving attention e.g. by telling the child off; this will only reinforce the behaviour. Deal with it in as swift and impersonal a manner as possible with minimal speech and eye contact.
- Alternate periods of 'work' and 'play' to give the child a break. 'Work' is chosen by the adult, 'play' by the child. Use a kitchen timer to define the sessions.
- Do not attempt to target too many aspects of behaviour at one time. Decide on one or two behaviours to focus on and make clear what is not acceptable and what is desired.
- Use First and Then boards, and/or visual timetables to reinforce expectations and routines.
- Give simple, limited choices. This gives children a sense of having some control, while ensuring that you keep the key requirement firm.
- Play partnering alongside the child and their peers – modelling appropriate play for both the child with Down syndrome and their peers.
- Play simple co-operative games that involve taking turns.
- Comic strips or social stories - comic strips can be used to help teach children other peoples' perspectives; they are a useful way to teach a child that not everyone thinks and feels the same.

You do not need to be an artist to draw them by hand – you can just use stick men and thought bubbles. The stories can be used after a specific event to teach an individual what went ‘wrong’, why the other person reacted the way they did, and how it made the other person feel. You will need to involve the child when drawing it – only they can tell how they perceive a situation.

Sensory and/or Physical Development

Children with Down syndrome often experience a delay in their motor development and have some specific weaknesses which need to be considered when offering them activities.

Key facts:

- Children often have delayed motor skills – fine and gross motor.
- Many children with Down Syndrome have a degree of floppiness of their muscles (hypotonia) and this affects each child to a different degree. Low muscle tone, as well as reduced strength and endurance, make it hard to learn gross motor skills.
- Children with Down Syndrome usually have increased flexibility in their joints (hypermobility), and you may first notice this in the child’s hips as their knees fall to the sides when they are lying on their back.
- Children with Down Syndrome sometimes take a long time to walk independently after they have learned to walk with support.
- It is harder for them to balance and co-ordinate themselves, as they do not get the same sensory information from their bodies, particularly if their muscles are very floppy.
- Neck instability - In those with Down syndrome ligaments tend to be lax and muscle tone is often low. This gives one vertebra the potential to move to a greater extent on its neighbour than is seen in the average person. As a consequence the nerve cells of the spinal cord can become distorted and injured.
<https://www.oxfordshire.gov.uk/sites/default/files/file/information-childcare-providers-toolkit/neckinstability1.pdf>
- Children who have Down syndrome are more prone to have difficulties with their hearing and vision. It is important to identify these early on, so that appropriate help can be given to minimise the effect of a hearing or visual impairment on the child’s development.
- The patterns of hearing loss presenting in Down syndrome change throughout life.

Strategies for supporting children with a hearing impairment:

- Use a bright encouraging face, possibly with exaggerated facial expressions and reactions but not exaggerated lip patterns.
- Make your voice fun to listen to and use an intonated voice (‘motherese’) as this is what young children like
- Talk and play close to children so that their hearing aids can pick up your voice. The closer you are the louder your voice will be- so you won’t have to shout
- Use calm strokes with calm voice; bouncy movements with lively voice
- Give lots of eye contact, face to face interaction and games that indicate, “I’m interested in you!”
- Use voice and then ‘touch’ to gain attention
- Make sure the child knows you are talking to them
- Smiles show you are enjoying it too

Strategies for supporting children with a visual impairment:

- Gwyn McCormack from Positive Eye shares simple activities you can do using everyday items to help children with vision impairment (VI) develop an understanding of objects, numbers and letters. <https://www.oxfordshire.gov.uk/sites/default/files/file/early-years/childcare/activitiesusingeverydayobjects.pdf>

Strategies to develop fine motor skills:

- Encourage the baby to weight bear on their arms and hands e.g. pushing up while lying on tummy.
- Encourage the baby to reach up when they are lying on their back.
- Provide a supportive sitting position so the baby can concentrate on exploring with their hands.
- Provide toys that the baby can hold and pass between hands.
- Provide cause and affect toys.
- Encourage the child to point at pictures or poke their finger into playdough.
- Ensure that when the child is holding an object that their thumb is tucked around the toy and not into their palm.
- Provide toys that come apart and fit together again.
- Provide toys that can be posted or fitted into slots e.g. posting boxes, shape sorters.
- Encourage a three fingered grasp (thumb and first two fingers) by playing with smaller toys e.g. peg boards or wooden blocks to stack.
- Introduce crayons and chinks; you may be able to buy triangular or special shaped markers e.g. Crayola Tadoodles.
- Use daily activities that encourage the child to hold something in the palm of their hand e.g. liquid soap into hand before washing.
- Do action songs and rhymes together e.g. clapping games.
- Do pouring activities in the bathtub or kitchen with water or dry food.
- Do activities where the child pushes and pulls, works against gravity and must exert some force e.g. climbing, pushing open doors, pushing a toy, helping to wash a car with a sponge.
- Introduce using scissors, demonstrate how to hold them and help the child get started.
- Encourage games and playing with toys where you use two hands together e.g. Duplo, Lego, threading beads.
- Sing action rhymes where individual finger movement are required e.g. Incy Wincy spider.
- Encourage the child to help with dressing/undressing themselves as much as possible.
- Encourage the child to eat with a spoon, fork and possibly knife.
- Provide toys with smaller parts (if this is safe) and where more precision and control is required e.g. coins into a piggy bank.

Strategies to develop gross motor skills:

- Reach and roll - children reach forwards with one arm, then roll over that arm, followed by reaching with the other arm then rolling over that side.
- Place toys just out of reach to encourage them to stretch forwards. Many children progress from this to pulling themselves forwards on their elbows (creeping).

- Commando crawling - on tummy, your hand over child's bottom, when they reach forwards with one hand, gently stop them from rolling on to their side and encourage them to lean to the other side and reach with that hand instead.
- Encourage pushing through feet - help them to learn this by placing your hands on the soles of their feet and push gently with alternate hands, encouraging the child to push back against you. When reaching with the right hand, encourage pushing with right leg and vice versa.
- Place a favourite toy / treat just out of reach to encouraging them to reach with one hand towards it.
- To develop a crawling place child in a crawling position, hands on the floor and provide support - use a rolled-up towel or your leg under their tummy. Gently hold child's knees together and bent underneath them.
- Gradually reduce support - place child in a crawling position, hands on the floor. Hold them around hips, and apply a gentle but firm downward pressure to maintain this position. Aim for no support under their tummy.
- Encourage legs together and not too wide apart, not pushing back with legs and supporting themselves on their arms.
- Later, encourage child to rock back and forth or side to side to develop balance.
- Encourage turning head to look for and reach a toy behind them.
- Encourage reaching between two pieces of furniture - place two pieces of furniture close together, position toys or treats on the other piece of furniture. Gradually increase the distance between the furniture and encourage stepping between them.
- Encourage squatting down from standing.
- Let the child stand holding your hands, then you let go of them once they have their balance.
- Encourage lifting both hands off the support to reach for toys.
- Play games encouraging the child to balance while you count or sing a song etc.
- Support the child when they begin to cruise. You can give support at hips, guiding weight on to one leg to help the child free the other leg to step. Help child position the leading leg out to the side, then guide them across to that leg. Allow, or help child to step the other leg across in the same direction.
- Encourage reaching sideways, stepping sideways, parallel to the surface
- Walk holding the child's hands at or below their shoulder level. Child holds on to your hands, with you standing in front.
- Use a towel / broom handle / hula hoop for the child to hold on to as their confidence increases.
- Encourage the child to pull themselves up on walkers.

SISS SPI Team – Support Pathway

RATIONALE:

SISS and EY Team colleagues identified the necessary support provided by education services within the Borough for Early Years children with Down Syndrome. This pathway offers clear guidance to outline the support that will be routinely provided from Early Years onwards to ensure all colleagues across all disciplines are able to accurately advise parents and carers of the support available.

1) Child with Down Syndrome

Health Visitor to refer child to TAC within 3 months of new birth visit

EY Team to take lead for support and complete transition into school up until October half term in the year they begin school.

SISS VI, HI, PD teams will be involved for vision, hearing or physical disabilities as per the eligibility criteria if the child meets need.

SISS SPI Team will send out annually into school, generic information sheet to assist with strategies/advise for specialist area of concern.

2) Child with Down Syndrome and additional Complex needs, sensory – Visual/Hearing needs and/or physical disability

Health Visitor stays involved as per HV criteria

Individual specialist teacher will lead dependent upon the complexity of need e.g. MSI or VI/HI and remain within eligibility criteria parameters for caseload allocation

At point of transition into setting, we continue with specialist support

- VI, HI or MSI to review support based upon eligibility criteria
- PD involvement only required if gross motor delay is significantly impacting upon mobility greater than expected for a child with DS / or if child is in mainstream and requires management plan

Charities, Advice & Support

Down Syndrome Association (DSA)

A national organisation, committed to improving the quality of life of people who have Down syndrome, promoting their right to be included on a full and equal basis with others. The Down Syndrome Association supports people who have Down syndrome, and their parents and carers, throughout their lives. From before birth into older age, the DSA provides services to everyone.

Langdon Down Centre, 2a Langdon Park, Teddington TW11 9PS

Helpline 0333 1212 300 Mon-Fri 10am – 4pm

Email: info@downs-syndrome.org.uk

<https://www.downs-syndrome.org.uk/>

Down's Heart Group

Advice and support for families with children with heart problems.

PO Box 4260, Dunstable, Beds. LU6 2ZT

Tel: 0300 102 1644

Fax: 0300 102 1645

Email: info@dhg.org.uk

<https://dhg.org.uk/>

Down Syndrome Education International (DSE)

Supports scientific research and delivers evidence-based advice and information to improve outcomes for children with Down syndrome worldwide.

6 Underley Business Centre, Kirkby

Lonsdale, Cumbria LA6 2DY

Tel: 0330 043 0021 Fax: 0330 043 0025

Email: hello@dseinternational.org

<https://www.down-syndrome.org/en-us/>

MENCAP

Supporting people with a learning disability and their families and carers. Offices in Peterborough, Wales and Northern Ireland.

123 Golden Lane, London EC1Y 0RT

Learning Disability Helpline: 0808 808 1111

Email: helpline@mencap.org.uk

<http://www.mencap.org.uk>

Down Syndrome Medical Interest Group (DSMIG U.K & Ireland)

The website has been developed primarily to equip healthcare professionals with the resources they need to help them provide good, evidence-based care for people with Down syndrome. Although designed for health professionals we hope it will be of interest and use to a wider range of people who are interested in promoting health and wellbeing of those with Down syndrome including parents and carers.

c/o Staff Library, Duncan Macmillan House,

Porchester Road, Nottingham NG3 6AA

Tel: 0115 969 1300 ext. 11186

Email: info@dsmig.org.uk

<http://www.dsmig.org.uk>

Developmental Journal for Babies and Children with Down Syndrome

This was part of the Early Support Programme which has now closed. The journal is still available at

<https://councilfordisabledchildren.org.uk/resources/all-resources/filter/schools-colleges-and-fe/downs-syndrome-development-journal-early>