

We are passionate about the inclusion, development and education of children and young people with Down syndrome. All of our training courses and support sessions are aimed at improving the lives of people with Down syndrome and working towards a more inclusive society

**Understanding Down syndrome – a guide to help you learn about the learning profile of a person with Down syndrome and methods to help with development**

### **WHAT IS DOWN SYNDROME?**

Down syndrome is a condition found in approximately 1 in every 700 to 900 births.

Children with Down syndrome are found across all social, economic and racial backgrounds.  Down syndrome is caused by the presence of an extra (third) copy of chromosome 21 at the time of conception.  Although the risk increases with maternal age, babies with Down syndrome are born to parents of all ages.  Indeed, the majority of babies with Down syndrome are born to women younger than 35.  Down syndrome is connected with a range of developmental difficulties which may include: delays in motor development; and specific difficulties with speech, language, numeracy, memory and cognitive development. Children and young people with Down syndrome achieve at a wide range of levels with some achieving well at GCSE.  Down syndrome is connected with a range of medical problems including increased risk of hearing and vision defects, heart abnormalities, infections and thyroid disorders.  However, with appropriate education, therapy, health care and social support, the majority of people with Down syndrome can lead long, independent and fulfilling lives in our communities and expect to live to between 50-60 years of age.

#### CHILDREN FIRST

Children with Down syndrome are children first.  Please always refer to them as “children with Down syndrome” not “Down’s children” or “Down’s kids”.

#### LEARNING AND TEACHING

Children with Down syndrome are visual learners; their visual memory is their strength. It is very difficult for them to learn through verbal instruction only. They need something visual to hold in their short-term memory. Verbal words exist only for an instant and cannot be retrieved. Think to yourself “it needs to go in through their eyes as well as their ears”. Differences in their brain functioning mean that they have difficulty processing and remembering information presented verbally.  All teaching and routines need to have some sort of visual support.

All children thrive on routine and this is especially so for children with Down syndrome-they require routine and

repetitiveness. Do not try to teach too much at once. Break each goal into small tasks and if necessary break each smaller task down again. This means that you need lots of simple, easy, short, visual activities prepared and ready that all teach the same small step again and again without being boring. Over learning and opportunities to revisit topics are needed to help consolidation. This promotes confidence and self esteem.  Teaching/support assistants may need help to differentiate activities in this way.  So time will be needed when assistant and teacher can plan. Once a few activities are ready it is easy to build on these ideas and prepare for the next step.

Remember

* Don’t panic. If the pupil is progressing slowly you only need to be one step in front of them
* Always have a “dry run” yourself making sure you have all the materials you need at hand
* Think about the language you are going to use – which words?  e.g. small, tiny, baby or little for the bear in Goldilocks.  Think about how you are going to make it visual ( signs, signing), objects, pictures, written word are all visual
* Take turns - this will visually demonstrate to the pupil what is expected
* Do not move the pupil on too quickly. Learning needs to be thorough, strong and consistent
* The pupil may be slow to respond (processing information in the brain takes a little longer and may not happen at all if information is verbal) - do not prompt too soon, give them time to answer/act
* Always have card/paper and pen at hand for visual prompts
* Have stickers or flashcards available if the pupil cannot write. These will reduce the task and enable the child to demonstrate he/she understands and knows the answer without having to write it down or verbalise clearly
* Use a sand timer to encourage the pupil to work for a set time
* Finish an activity on an achievement.  If the pupil is loosing interest finish and praise with sign and speech. ‘Good work, well done, finished’
* Try to keep the pupil included in the classroom as much as possible, so that they are working with their peers on age appropriate material and tasks, especially as they get older. Encourage age appropriate behaviour
* Make sure that the pupil is sitting at the front, near to the teacher and white board
* If working in small groups, it is better to group the pupil with more able peers than with other weak/slow learners. Other pupils are a good resource they make very good role models/teachers
* Be careful that the teaching/support assistant is not used entirely for one-to-one sessions. The teacher too, has a responsibility to teach pupils with special educational needs.

### **OTHER POINTS TO REMEMBER**

#### VISUAL/PICTORIAL COMMUNICATION SYSTEMS

As indicated above pupils with Down Syndrome are very much visual learners so when it comes to language development and communication, visual word reinforcement is essential.  A communication system using signing alongside the spoken word, for example Makaton, will encourage the reinforcement of key words both visually and verbally. The child will then be more focused on your verbal instruction. Pictures can also be used as visual prompts. Pupils with Down syndrome are highly sociable and want to communicate; they are good at gesture and therefore, generally pick up signing quickly. They may have been using signing to communicate their needs from an early age. It is therefore important to realise that signing has many uses:

to help the child understand your instructions

to help the child’s communication to be understood;

to enable you to grab the child’s attention when speaking to them; and

to help develop language and introduce new vocabulary.

The pupil’s understanding will often be more developed than their speech and language abilities.  Do not assume that the pupil does not understand you because of their poor language skills.  Pupils who are not using a clear verbal language or signs to communicate their needs may communicate using gesture or inappropriate behaviour rather than language since this draws attention. If a child is having difficulties communicating their needs, and signing has not been introduced, it may be worth discussing the issue with parents - you could train alongside them.

#### INFORMATION COMMUNICATIONS TECHNOLOGY (ICT)

Using a computer can be highly motivating and can often sustain a pupil’s attention for longer periods. Learning using the computer is visual, interactive, allows non-verbal responses and also reduces the need for the kind of precision of fine motor skills that traditional reading, drawing and writing requires, hence bringing independence to learning which in turn brings self-esteem. Many good programmes are now available to meet the needs of such learners.

#### NUMICON

A highly effective visual tool for teaching mathematics from an early age. Courses are now available through the Down Syndrome Training and Support Service ltd.

#### READING AS A VISUAL AID TO SPEECH AND LANGUAGE DEVELOPMENT

Pupils with Down syndrome can be taught to sight read from an early age. The written word, like a sign, is used as a visual prompt. However, it is more powerful in that it can go a few steps further and help not only introduce new vocabulary but also grammatically correct phrases/sentences and help to improve clarity of speech. Books and sentence strips can be made to introduce these concepts. However, take care not to do all of this at the same time. Introduce only one new word or phrase at a time and work on improving pronunciation of words that are already well established in the child’s vocabulary. Again, training in using visuals tom support development of language and communication is available from the Down Syndrome Training and Support Service ltd.

#### CONVERSATION DIARY

The conversation diary is like the child’s version of the home-school diary and should include a short sentence spoken by the child in response to your question (which may have to be made visual) “what did you do today?” if the response is “play ball” you write “I played ball” or “I played with the ball”. The child should remember this and be able to “read” it because it is what they tried to say. Include a picture of the ball drawn by you or the child or even a digital photo. This diary can be developed over the years to include day, date, time etc and is a fantastic personal resource that can be used to develop language.

#### IN GENERAL

In general be prepared. Making the place where the pupil sits visual may help - a coloured circle with their name

on it for carpet time, stick their name on their chair or desk space.  When planning lessons think about how you can

make it more visual, pictures, objects, sign key words (the rest of the class will enjoy this), written words using clear, large type and picture prompts. A daily, and later weekly, chart visually listing activities will be useful and help develop routine and guide the child through transition between activities.

#### BEHAVIOUR

It is important to remember that a pupil with Down syndrome has a different way of learning - exposing them to an education designed for a typically developing pupil and teaching as though the disability does not exist may well encourage unwanted behaviour. In addition their language delay may result in using behaviour to communicate.

Gestures are so much easier than speech and if they are feeling unhappy about something and cannot communicate this they will show how they feel through behaviour. If the pupil is included and engaged in the classroom activities they will be far less likely to exhibit unwanted behaviour.  If unwanted behaviour persists it may be necessary to introduce a behaviour management plan.  Liaise with parents. All approaches to modifying behaviour must be consistent and the same methods of dealing with unwanted behaviour must be used both at school and at home.  Other pupils encouraging inappropriate behaviour need to understand how unacceptable this is.  Be careful not to ‘baby’ the pupil with Down syndrome, i.e. sitting on the knee. If inappropriate behaviour is modelled the pupil will respond as you would expect them to i.e. with immature behaviour.

#### SELF ESTEEM AND FRIENDSHIPS

Praise ALL success. Pupils with Down syndrome are often more sensitive to failure than other pupils.  Design some class activities in which the pupil can do well. This will show their peers that they CAN achieve. Like most pupils, if they do not get the opportunity to enjoy success it is highly likely that they will ‘turn off’ and begin to avoid tasks and appear stubborn and withdrawn - wouldn’t we all!
Strive for ‘errorless learning’ – this helps to promote self-esteem and confidence. There are key transition stages for all pupils (moving class/room, year group or schools).  It is particularly important that these are well planned for children with Down syndrome, as previously stated, they enjoy routine and consistency.  Schools have found that ‘buddy schemes’ or small friendship groups work very well, especially at the more unstructured times of the day: lunchtime, snack-time etc. Do plan for these occasions.  When possible also plan with parents and peers, ‘home invites’.  This contributes significantly towards the aim of belonging to and contributing to life in the community.  The programme ‘A Circle of Friends’ is well worth looking into and developing in school. Pupils with Down syndrome experience puberty at the same time as their typically developing peers and this should be a positive experience.  They need to know how to feel good about themselves and their bodies.  Their vulnerability to being sexually abused or exploited is a particular area of concern.  [Training](http://www.downsyndromebradford.com/training/) is regularly delivered at the Pamela Sunter Centre in Bingley.

### **OTHER RELATED MATTERS - HEALTH**

#### HEARING

Approximately 80 to 90% of children with Down syndrome may experience conductive hearing loss. This can compound the difficulties of learning through verbal instruction. (Note that signing is used to aid visual learning and not used to compensate for poor hearing.) Even the slightest loss of hearing can affect a child with Down syndrome, unlike his/her typically developing peers who will have the ability to compensate. Any suspected hearing problems should be discussed with parents and the school nurse.

#### EYESIGHT

Almost all people with Down syndrome will have some form of visual impairment, whether they need glasses or not they see the world slightly more blurred, therefore visual acuity is reduced.  They will not see the same level of detail

and will find it difficult to discriminate between low contrasts. There are recommendations from the Cardiff research team that children with Down syndrome, who show poor focusing skills, be prescribed bifocal lenses.

#### OTHER PROBLEMS

Because Down syndrome is a condition affecting every cell in the body it may affect muscle tone. Many children are hypotonic. This means that as babies they may be very floppy and poor muscle tone may delay walking.  Running and other physical activities may be difficult to master.  This poor muscle tone can also affect the bowels and constipation may be a problem. Parents may wish to know details of what has been eaten and if they have been to the toilet etc. Toileting - some children may be late to master this. All staff need to be aware that training may be ongoing. Plan your approach with parents. Approximately 40% of children with Down syndrome are born with a heart defect, some will have had major surgery early in life and some may be awaiting surgery. Correction of such defects is very successful. Because passageways also tend to be narrower ears, nose and throat are prone to more infections, compounding hearing loss. Always have a box of tissues handy and have a plan in place for the day if they have had a bad nights sleep and are feeling congested. – none of us like to feel like this and school life can be very demanding!

### **THERAPIES**

#### SPEECH & LANGUAGE

The great majority of children with Down syndrome have difficulties with their speech and language and may require specialist speech and language therapy. An assessment by a trained therapist is essential and regular individual intervention is often required. Guide lines recommended by the Down Syndrome Education International are available (details given below).

#### PHYSIOTHERAPY

As mentioned many children with Down syndrome are hypotonic - this may result in poor coordination and delayed development in fine and gross motor skills. Their gross motor skills may cause them to be later to walk than typically developing children. However they will run, ride a bike etc but maybe not as soon as their typically developing peers. Discuss concerns with parents who will have been attending physiotherapy with their child since birth.

Fine motor skills may also be a problem. Many children find writing very difficult and use a computer or other methods (e.g. stickers, cards with words written on them to order and stick in an exercise book, pictures) to help record work. A paediatrician occupational therapist may be able to help.