

Including pupils with Down's syndrome

Information for Teachers and Support Staff

- Early Years



HELP FOR PEOPLE WITH DOWN'S SYNDROME



**DOWN'S
SYNDROME
ASSOCIATION**

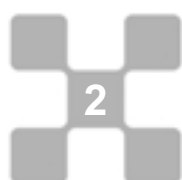
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Down's Syndrome

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Introduction

Most children with Down's syndrome enjoy attending their local preschool, nursery or playgroup and most of the basic building blocks to prepare children for inclusion into mainstream school can be learnt in these environments. In the early years, the prime aim is social inclusion. Children with Down's syndrome who mix with typically developing peers in their locality, benefit not only themselves but also the other children in that community. While they will undoubtedly learn from typically developing children who provide role models for age appropriate behaviour and achievement, they may need additional help and support.

The majority will be at an earlier developmental, social and emotional stage than their peers, due to their learning difficulties. Moreover, they are unlikely to pick up conventions intuitively. As a consequence, their understanding of the world will be less advanced and their behaviour may be more on a par with younger children. It is also much harder for any child to make progress in cognitive areas until they are able to behave and interact with others in a socially acceptable way and to understand and respond appropriately to the immediate environment.

The focus of additional help and support in the early years should therefore be on learning the rules for normal and appropriate social behaviour. Social inclusion aims for the young child with Down's syndrome include:

- Learning to participate and respond.
- Responding to verbal requests and instructions.
- Learning typical patterns of behaviour e.g. taking turns and sharing, lining up, sitting.
- Learning to play co-operatively.
- Developing independence: self-help and practical skills.
- Developing friendships.
- Caring for others.

Children with Down's syndrome often have shorter concentration spans than their peers. They also have more difficulty processing input from more than one sense at a time (e.g. copying and listening), which inhibits their ability to focus. These difficulties are particularly apparent in the early years and many youngsters with Down's syndrome may be distractible, flitting from one activity to another. The less focused and more informal the situation, the more difficult it will be for the young child to channel attention into one activity for a length of time. However, children with Down's syndrome do respond well to structure and routine and are able to learn these well. Teaching them the routine and structure of their day with the aid of strong, clear visual cues (e.g. photographs and objects of reference) can help children learn. By these means, they can understand their environment better, learn appropriate behaviour for particular sessions and activities and predict the next activity. Difficulties with understanding verbal explanations and instructions are also overcome.



Aim of this booklet

The majority of children with Down's syndrome are now entering mainstream preschool settings. While most early years workers will be looking forward to receiving a child with Down's syndrome, some may, initially, be a little apprehensive. However, experience shows that most early years workers have the skills to understand these children's particular individual needs and are able to include them effectively and sensitively. This booklet is designed to inform practitioners about the learning profile typical of young children with Down's syndrome, and about good practice in their education, thus paving the way for successful inclusion.

Why Inclusion?

There are many reasons why a child with Down's syndrome should be given the opportunity to attend a mainstream preschool setting. Increasing amounts of research have been published enhancing knowledge about the capabilities of children with Down's syndrome in the mainstream, and their potential to be successfully included, while parental awareness of the value and the benefits of inclusion has grown. Moreover, inclusion is non-discriminatory and brings both academic and social benefits.

- Research shows that children learn more effectively when working in inclusive settings.
- Daily opportunities to mix with typically developing peers provide models for typical and age-appropriate behaviour.
- Young children have the chance to develop relationships with others from their local community.
- Attending a mainstream setting is a key step towards inclusion in the life of the community and society as a whole.

Successful inclusion is a critical step in preparing children with learning difficulties to become full and contributing members of the community, and society as a whole benefits. Typically developing peers gain an understanding about disability, about tolerance and how to care for and support other children with special needs.

A Positive Attitude

Successful inclusion does not happen automatically. Experience shows that one of the most important ingredients in successfully implementing inclusion for children with special needs is simply the will to make it succeed. The attitude of the whole setting is therefore a significant factor. Preschools and nurseries need a clear and sensitive policy on inclusion and managers that are committed to the policy and supportive towards their staff, helping them develop new skills.

Before admitting the child, take time to talk to the parents and ask permission to contact the family health visitor, Portage worker, Speech & Language therapist and any other agencies already involved. Find out from them what they are working on and whether they will continue to be involved once the child starts with you.

Some facts about Down's syndrome

- Down's syndrome is the most common form of learning disability caused by a chromosome abnormality - about 1 in every 1,000 babies born each year has Down's syndrome.
- It is caused by the presence of an extra chromosome. Instead of the usual 46 chromosomes, a person with Down's syndrome has 47. As this is on chromosome 21, people with Down's syndrome are said to have trisomy 21. In 96% of births this has happened at conception so every cell and system of the body is affected by it. This accounts for the characteristic physical features as well as the specific learning profile.
- In about 1 in 100 births of babies with Down's syndrome, the extra chromosome 21 appears at some point in the foetal development – thus only a percentage of the cells have the trisomy 21, and a percentage of the cells are typical. This is called Mosaic Down's syndrome. People with Mosaic Down's syndrome tend to be at the higher ability end of people with Down's syndrome, although some people with the usual trisomy 21 can also be as able.
- Although Down's syndrome is a chromosome abnormality, environmental factors play an important part in development, as with any child.
- All children with Down's syndrome will have some degree of learning difficulty ranging from mild to severe. A small percentage of people with Down's syndrome will be functioning at the lower end of the average ability range. Similarly a small percentage will have profound and multiple learning difficulties. Most will fall between these two extremes.
- Children with Down's syndrome vary as widely in their development and progress as typically developing children. Each person is a unique individual with their own personality and interests. Among their many attributes they also happen to have Down's syndrome which will affect them to a greater or lesser extent – so get to know your child first before jumping to any conclusions. Generally speaking, children with Down's syndrome develop more slowly than their peers, arriving at each stage of development at a later age and staying there for longer. The developmental gap between children with Down's syndrome and their peers widens with age.

A specific learning profile not just developmental delay

Children with Down's syndrome are not just generally delayed in their development and are not merely in need of a diluted programme. They have a specific learning profile with characteristic strengths and weaknesses. Being aware of the factors that facilitate and inhibit learning will allow staff to plan and implement meaningful and relevant activities and programmes of work.

The characteristic learning profile and learning styles of the child with Down's syndrome, together with individual needs and variations within that profile, must therefore be considered. The following characteristics are typical of many children with Down's syndrome. Some have physical implications; others have cognitive ones. Many have both.

Factors that facilitate learning

Strong visual awareness and visual learning skills, including the ability to:

- Learn and use sign, gesture and visual support.
- Copy the behaviour and attitudes of peers and adults.
- Learn from hands-on activities.

Factors that inhibit learning

- Delayed motor skills - fine and gross.
- Auditory and visual problems.
- Speech and language difficulties.
- Poor short-term auditory memory.
- Short concentration span.
- Avoidance strategies.

A brief account of each of these inhibiting factors follows, with some strategies to address them which make use of the child's likely strengths and weaknesses, in order to build a successful programme. Many of these strategies will be recognisable as basic good practice and so will be equally suitable for other children in your setting.

Visual impairment

Although children with Down's syndrome tend to be very good visual learners, many have some sort of visual impairment: 60-70% being prescribed glasses before the age of seven. However, visual defects in children with learning disabilities are often not picked up, as it is assumed that any difficulties in learning or behaviour are due to the learning disability. It is important, therefore, to make sure vision is checked in the early years at least every six months and allowances made for any specific visual impairment they may have. Studies have shown that around 73% of children with Down's syndrome have poor focusing skills and reduced acuity (detailed vision) compared with their typically developing peers, even when significant long or short sight is corrected with glasses.

Strategies:

- *Encourage the parents to consider bifocals for their child.*
- *Place the child near the adult in group work.*
- *Provide enlarged images and pictures.*
- *Use bright colourful games and learning materials.*



Hearing impairment

Many young people with Down's syndrome experience some hearing loss, especially in the early years. Up to 20% may have a sensorineural loss, caused by developmental defects in the ear and auditory nerves. Over 50% are likely to suffer from a conductive hearing loss due to glue ear caused by frequent upper respiratory tract infections. These often occur as a result of smaller sinuses and ear canals. It is particularly important to check a child's hearing, as this will affect their speech and language development. Clarity in hearing can also fluctuate daily and it is important to determine whether inconsistencies in response are due to hearing loss rather than lack of understanding or poor attitude.

Strategies:

- *Place the child near the adult in group work.*
- *Speak directly to the child.*
- *Stress word beginnings and endings.*
- *Reinforce speech with facial expression, sign or gesture.*
- *Reinforce speech with visual backup - print, pictures, concrete materials.*
- *When other children answer, repeat their answers aloud.*
- *Rephrase or repeat words and phrases that may have been misheard.*

Fine and Gross Motor Skills

Activities that depend on gross and fine motor co-ordination skills (sitting, crawling, walking, running, manipulating toys, feeding/drinking independently, etc.) increase a child's opportunities to find out about their world. Therefore, it is important to bear in mind that any delay in motor development in the early years is likely to restrict cognitive development. Children with Down's syndrome tend to have lax muscle tone (hypotonia). In addition they are slower at motor processing. As a result, children with Down's syndrome may have more difficulty participating in games than their peers. They will also find it hard to manipulate small pieces of equipment and to engage in drawing and pre-writing activities. As a consequence, they are likely to need additional help in developing their motor skills and benefit from a wide variety of materials, e.g. adapted scissors, extra thick chunky pencils and pencil grips, large knob inset puzzles etc. They also benefit from a wide range of multi-sensory activities.

Strategies

- *Make sure seating allows the child to rest their feet on a solid surface e.g. the floor or a step.*
- *Encourage the child to extend their gross motor skills e.g. pedalling a tricycle, climbing steps, throwing and catching a ball.*
- *Offer lots of activities to develop fine motor control e.g. threading, Duplo, pegboards etc.*
- *Encourage large movements in a sand tray or on a whiteboard, to help the development of prewriting skills.*



Speech and Language Difficulties

Most children with Down's syndrome have some degree of speech and language impairment. Most will start to speak between the ages of two and three. However, the vast majority manage to communicate extremely well from an early age with very little or no use of spoken language, relying on sign, gesture and body language. These language learning difficulties result in a smaller vocabulary and less general knowledge, delaying other aspects of cognitive development.

The language delay is caused by a combination of factors, some of which are physical and some due more to perceptual and further cognitive difficulties. Any delay in learning to understand and use language is likely to lead to cognitive delay. Receptive skills are generally greater than expressive skills. This means that most children with Down's syndrome understand language better than they are able to speak it. As a result, their cognitive skills are often underestimated. Estimates of ability are likely to be depressed further by poor articulation and dysfluency (stammering), both common in young people with Down's syndrome.

Children with Down's syndrome are not able to use language for thinking, reasoning and remembering to the same extent as most other children of the same age. To encourage and develop their speech, it is vital that every opportunity is given to aid communication and understanding. In addition, they should be seen regularly by a Speech and Language Therapist who can suggest individualised activities to promote their speech and language development and improve the clarity and fluency of their speech.

Teaching children with Down's syndrome to use signs and gestures (such as Makaton or Signalong) is an immense aid to both a child's understanding and ability to communicate. Signs and speech are used together: as the child becomes more able to say the words, the signs are dropped, often by around the age of five.

To ensure the effectiveness of any signing system, it is important that:

- All adults in the setting are familiar with the basic signing vocabulary and use it alongside speech when talking to the child.
- The other children are introduced to the basic signs and are encouraged to use them.
- The parents are encouraged to sign and speak to the child at home.

Common features of delay in language acquisition:

- Difficulty in understanding instructions.
- Smaller vocabulary leading to less general knowledge.
- Difficulty learning the rules of grammar (leaving out connecting words, prepositions etc.) resulting in a telegraphic style of speech.
- Greater problems in learning and managing social language.

In addition, the combination of having a smaller mouth cavity and weaker mouth and tongue muscles makes it harder for them to physically form words. The longer the sentence, the greater the articulation problems become.

Speech and language problems for these children often mean that they actually receive fewer opportunities to engage in language and conversation. It is more difficult for them to ask for information or help. Adults tend to ask closed questions or finish a sentence off for the child, without giving them much needed time or help to do it themselves.

This results in the child getting:

- Less language experience to enable them to learn new words and sentence structures
- Less practice to improve their clarity of speech.

Strategies:

- *Give the child time to process language and respond – try to leave at least five seconds for a response – you will be surprised at what the child has retained!*
- *Listen carefully - your ear will adjust.*
- *Ensure face to face and direct eye contact.*
- *Use simple and familiar language and short concise sentences.*
- *Check understanding - ask the child to repeat back instructions.*
- *Avoid ambiguous vocabulary.*
- *Reinforce speech with facial expression, gesture and sign.*
- *Reinforce spoken instructions with print, pictures, diagrams, symbols, and concrete materials.*
- *Avoid closed questions and encourage the child to speak in more than one-word utterances.*
- *Encourage child to speak aloud by providing visual prompts.*
- *Use concrete materials e.g. puppets, picture Lotto, feely bags etc. to promote language development.*

Poor auditory short-term memory and auditory processing skills

Other speech and language problems in young children with Down's syndrome stem from difficulties with their auditory short-term memory and processing skills. The auditory short-term memory is the memory store used to hold, process, understand and assimilate spoken language long enough to respond to it. Any deficit in short-term auditory memory will greatly affect the child's ability to respond to the spoken word or learn from any situation entirely reliant on their auditory skills. In addition, they will find it more difficult to retain and follow spoken instructions. To overcome some of these memory problems, research has shown that introducing new words into the child's spoken vocabulary via the written word can be highly effective. Teaching young children with Down's syndrome to read can help their speech, as the written word serves as a visual prompt.

Strategies:

- *Limit amount of spoken instruction given at any one time.*
- *Allow time for the child to process and respond to verbal input.*
- *Simplify and repeat individually to the child any information/instructions given to the group as a whole.*
- *When teaching new vocabulary, use concrete objects or photographs of real objects, not drawings.*
- *Pair the object or photograph with the written word on a flash card using lower case not capital letters.*
- *Teach new words using the 'match, select, name' method.*

Remember: children with Down's syndrome are strong visual but poor auditory learners. Wherever possible, they need visual support and concrete and practical materials to reinforce auditory input.

Shorter concentration span

Many children with Down's syndrome have a short concentration span and are easily distracted. They also tire more easily than their peers, particularly if closely supported or taught on a one:one basis for lengthy periods of time.

Strategies

- *Offer a range of short, focused and clearly defined tasks.*
- *Change the activity regularly.*
- *Give the child frequent breaks from adult directed tasks.*
- *Encourage peers to play with or alongside the child.*

Generalisation, Thinking and Reasoning

Where any child has a speech and language impairment, thinking and reasoning skills are inevitably affected. They find it more difficult to transfer skills from one situation to another.

Strategies

- *Do not assume that the child will transfer knowledge automatically.*
- *Teach new skills using a variety of methods and materials and in a wide range of contexts.*

Consolidation and Retention

Children with Down's syndrome generally take longer to learn and to consolidate new skills and the ability to learn and retain can fluctuate from day to day.

Strategies

- *Provide extra time and opportunities for additional repetition and reinforcement.*
- *Present new skills and concepts in a variety of ways, using concrete, practical and visual materials wherever possible.*
- *Move forward but continually check back to ensure that previously learned skills have not been overwhelmed by the new input.*

Structure and Routine

Many children with Down's syndrome thrive on routine, structure and clearly focused activities. Unstructured and informal situations are often more difficult for them. Equally, they can be easily thrown by any change. They may need more preparation and may take longer to adapt to changes in the room and to transitions from one activity to another.

Strategies

- *Teach timetable, routines and rules explicitly, allowing time and opportunities to learn them.*
- *Provide visual timetables with pictures of the activity or photos of the child taking part.*
- *Ensure the child is aware of the next activity, use objects of reference e.g. a cup for snack time.*
- *Stick to routine as much as possible.*
- *Prepare the child beforehand if you know there is going to be a change, and inform parents.*

Behaviour

There are no behaviour problems unique to young children with Down's syndrome. However, much of their behaviour will be related to their level of development. So, when problems occur, they are generally similar to those seen in typically developing children of a younger age.

In addition, children with Down's syndrome have grown up having to cope with more difficulties than many of their peers. Much of what they are expected to do in their everyday lives will have been 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.

The thresholds that trigger problem behaviours may therefore be lower than with their typically developing peers, i.e. they are likely to become frustrated or anxious more easily. Therefore, while having Down's syndrome does not lead inevitably to behavioural problems, the nature of their difficulty makes them more vulnerable to the development of inappropriate behaviours.

A particular aspect of problem behaviour is the use of avoidance strategies. Research has shown that, like many children with special needs, those with Down's syndrome tend to adopt such strategies, which undermine the progress of their learning. Some children tend to use social behaviours to distract adult attention and avoid learning and seem prepared to work only on tasks which fall within a very narrowly defined range. It is important to remain alive to the possibility of avoidance, to separate immature behaviour from deliberately inappropriate behaviour, and to ensure that the child's developmental, not chronological, age is taken into account, together with their level of oral understanding. Any reward offered also has to take account of these factors.

Inappropriate behaviour may be due to:

- Attention seeking, particularly if the child is not used to working in a group, sharing or taking turns.
- Confusion or uncertainty, when the child is not clear what is expected or has failed to understand or remember what they have been told.
- Anger or frustration, when they are regularly withdrawn from their friends for special work or are given tasks that are too difficult or too easy.
- The need to control, when the child is given little choice or is over supported.
- Immaturity, when the child is not developmentally ready for a task such as toilet training or co-operative play.

Strategies

- *Make sure the rules are clear.*
- *Ensure that all staff are firm and consistent at all times.*
- *Agree the name of a key person who will act as first point of contact in cases of difficulty.*
- *Distinguish the “can’t do” from the “won’t do”.*
- *Investigate any inappropriate behaviour, asking yourself why the child is doing it.*
- *Ignore attention-seeking behaviour within reasonable limits and catch them being good and praise them.*
- *Reinforce the desired behaviour immediately with visual, oral or tangible rewards.*
- *Make sure the child is working and playing with peers who are acting as good role models.*

Support

Most young children with Down’s syndrome in early years settings will need some additional support, although this may not require the provision of extra staff. All staff in the setting should be familiar with the child’s needs and able to work successfully with them.

Strategies

- *Be aware that too much one-to-one support can result in the child failing to:
Benefit from the stimulation and models provided by the peer group.
Learn to play co-operatively.
Become independent.
Develop social relationships with their peers.*

Planning support

All staff need to meet regularly to plan, communicate, feedback and monitor progress. A communication book for all involved to record plans, notes, ideas and feedback is often invaluable, especially where more than one person is involved with the child. Remember to list successes as well as concerns.

When planning support, it is important to decide:

- Which activities will require adapting or differentiating?
- Who will differentiate activities and how?
- Who is to find or make additional resources?
- When this is to happen and how often?

Plan an Individual Learning Plan (ILP) to target specific areas needing special attention.

Liaison with outside agencies

Most preschool children with Down's syndrome will be under the care of a variety of professionals and staff will need to work closely with them to ensure the best possible outcomes for the child.

These could include:

- Speech and language therapists who will ideally work with the child in your setting and help you modify your practice to meet the child's needs. They should also be able to help you develop your knowledge and use of sign language, help with feeding problems and problems such as dribbling or stammering.
- Physiotherapists or occupational therapists who should be able to advise you on seating, physical activities, and hand-eye co-ordination.
- Paediatricians, school doctors or health visitors who may be monitoring heart problems, hearing, vision, toileting or other physical difficulties.
- Clinical psychologists or community nurses, who could be working with the family to reduce home based behaviour problems.
- Educational psychologists, who may be assessing the child as part of the formal assessment process leading to a Statement of Special Educational Need. They could also help you with nursery based behaviour or learning difficulties.
- Portage workers, area SENCOs or preschool advisory teachers, who can advise on curriculum planning, target setting, resources etc.

The Curriculum

In the early years, there is no reason why the majority of young children with Down's syndrome cannot take part in the full range of ordinary activities, albeit with a bit of additional support. However, the focus should be on improving social skills and independence.

Targets chosen to work on should include:

- communication
- mobility
- play
- socialisation
- independence
- self-help and
- inclusion in the life of the preschool setting.

Withdrawal and specialised, separate work should be kept to a minimum. Where children need to be withdrawn for short periods, they should be encouraged to bring a friend or work in a small group.

Developing play skills

Many children with Down's syndrome will need to be taught how to play with nursery equipment, how to play with other children and how to develop their imagination. They may lack confidence in a new setting or lack the understanding or motor skills of their peers. At first they may stick to one or two activities and be reluctant to try anything new. They may dislike getting their hands wet or dirty or become distressed by the noise and bustle of your setting. The best approach here is to slowly introduce new activities, teaching the skills required and using other children as a model. However, allow the child to progress at their own pace and don't worry if it takes time to build their confidence.

Developing IT skills

Computers have proved of real value to young children with Down's syndrome, utilising their visual strengths while giving them the opportunity to progress at their own speed. Many companies now produce excellent early years software which is colourful and breaks tasks down into manageable steps. Programmes are now available covering early language development and basic thinking skills.

Similarly, adaptations such as touch screens can be obtained, making the computer accessible to very young or disabled children, unable to cope with a basic keyboard.

Developing self-help skills

All children should be encouraged to become as independent as possible from an early age. Parents should be advised on sending the child to nursery in clothes that are easy to take off and put on again. Snack and meal times should be used to give the child practice in drinking from a cup and through a straw and eating with their fingers, with a spoon and in time with a knife and fork. Some children in the early stages may still need help in feeding themselves at all, and may be unable to swallow solids or chew.

Here the advice of outside specialists should be sought. Toilet training should not be attempted until the child is both physically and cognitively ready. Physically the child must be able to hold their urine for at least an hour and preferably two. This can be tested by feeling the nappy at appropriate intervals. Cognitively they must have linked the physical sensation with the idea of doing a wee. They would usually indicate this knowledge by telling you when they are wet or dirty or pulling at their soiled nappy. Many children with Down's syndrome are not ready to be toilet trained until they are 4 or 5 or occasionally beyond.

Transition to school

As the child approaches school age it is important that parents are helped to:

- Choose an appropriate school, preferably one where their siblings or friends from preschool will be going.
- Make sure the child's Statement of Special Educational Need is finalised and appropriate levels of provision specified.
- Take their child on a series of visits to the school to familiarise them with the people, the environment and the routine.

In addition you should:

- Visit the school to anticipate any problems that might arise.
- Invite school staff to visit your setting and see the child in a familiar environment.
- Involve the Portage Service or Preschool teacher in transition planning.
- Work with the parents to prepare a short piece about the child, with:
 - a photograph,
 - descriptions of favourite activities,
 - family pets,
 - preferred ways of working,
 - things they find too difficult etc.

This should be laminated and passed on to the new school for all staff to read.

- Practice any unfamiliar routines that will be required in school e.g.
 - sitting on the carpet
 - lining up
 - changing for different activities e.g. P.E., painting, going out.

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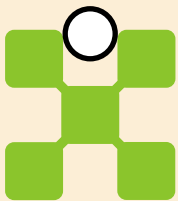
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If you can, **please make a donation** of any amount so we can continue to supply information free to those who need it. Thank you.

If you would like further information on the Down's Syndrome Association, or are interested in joining as a member, please give us a call on the number below.

Down's Syndrome

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