

Unit 1: Introduction

a) Down syndrome today

Each year, more children with Down syndrome than ever before are entering community playgroups and nurseries, attending their local mainstream school and joining in social activities with typically developing siblings and friends.

Each year more young adults with Down syndrome are living in the community, gaining qualifications and experiences and succeeding in a wide variety of ordinary jobs.

Given the chance to develop their self-help skills and independence, people with Down syndrome can respond positively to many of today's challenges in mainstream schools, colleges of further education, employment and independent living.

While many will need some support to benefit from the opportunities on offer, the amount of help they need will vary greatly from one individual to another.

The important fact is that increasingly children and adults with Down syndrome are being recognised as people in their own right, able to participate in meaningful ways to the life of their communities.

This is a very different state of affairs from that which existed in the UK prior to 1970, when children with Down syndrome were considered ineducable and were often placed in institutions where they lived out their relatively short lives.

Expectations of these children were low and they received little in the way of support, stimulation or social experiences. As a consequence, they often failed to develop into confident individuals with the skills necessary to promote their inclusion in the wider community. Instead they stayed in their institutions separated from family and friends.

Over the last thirty years, research has increased our knowledge about the capabilities of people with Down syndrome. At the same time, significant advances in health care, early intervention and family support have vastly improved the quality of life for young people with Down syndrome and their families, with most parents opting to bring up their disabled child alongside typically developing siblings.

Major changes in education law have given children with Down syndrome the right to full time education. In the early days, most were placed in special schools. However, in recent years, a steadily increasing number are being educated in the mainstream. As a result, expectations of individuals with Down syndrome have increased, alongside greater acceptance by society at large. Professor Sue Buckley sums up the situation thus:

"Individuals with Down syndrome are people first, with the same rights and needs as everyone else. Their development is influenced by the quality of care, education and social experiences offered to them, just like all other people."

b) Some basic facts

- Down syndrome is the most common identifiable cause of learning disability.
- Two babies with Down syndrome are born every day in the UK – about 1 baby in around 1,000 live births.
- Down syndrome is a genetic condition caused by the presence of an extra chromosome 21. A baby born with Down syndrome thus has three copies of chromosome 21 instead of the usual two.
- In most people with Down syndrome, every cell in the body has the extra chromosome (standard Trisomy 21). In 1-2% of babies, only some cells will contain the extra

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chromosome (mosaic Trisomy 21). However, in either case, the effects of the extra genetic material are likely to be very much the same.

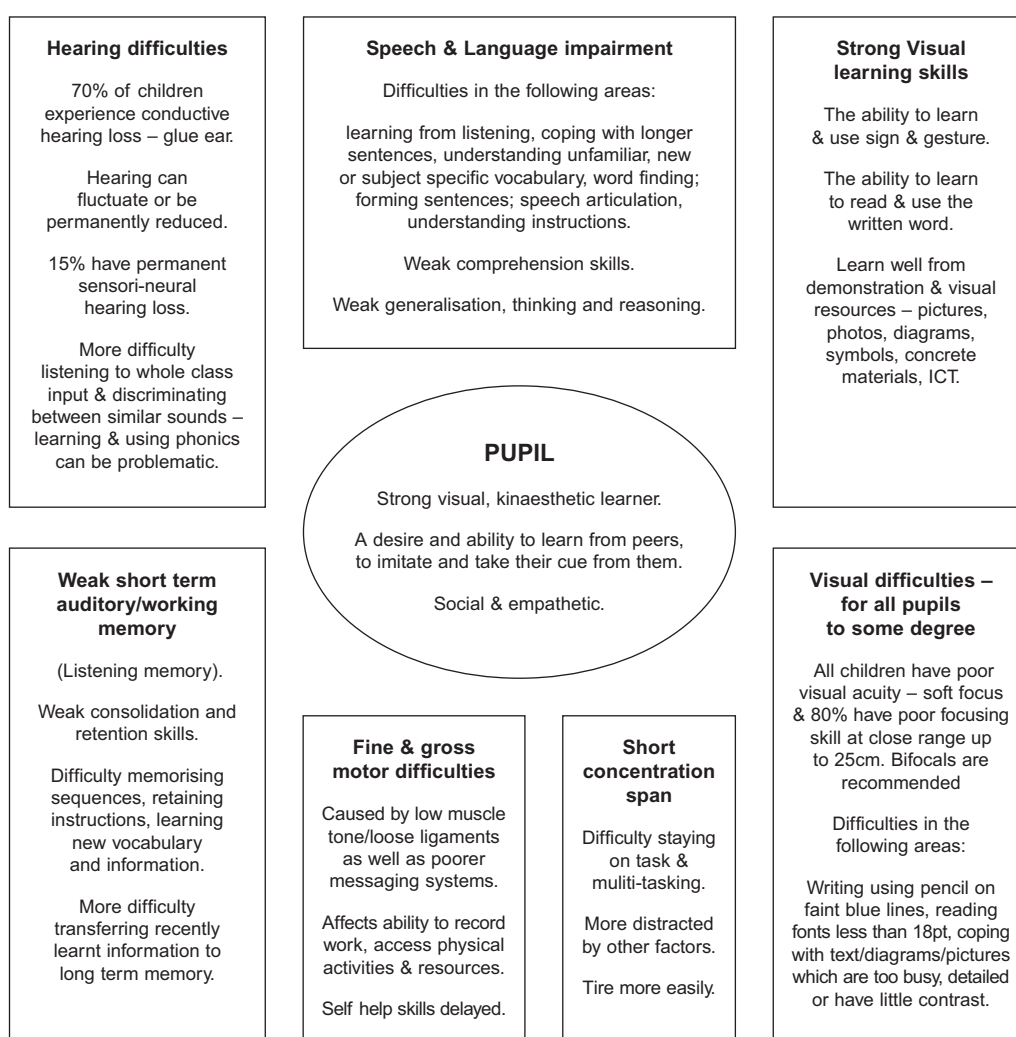
- Generally speaking, children with Down syndrome develop more slowly than their peers, arriving at each stage of development at a later age and staying there for longer. Consequently, the gap between children with Down syndrome and their peers will widen with age. The degree of delay varies across developmental areas – motor, social, communication, cognition and self help. This is described as a specific profile associated with the condition – or a pattern of strengths and weaknesses. However children with Down syndrome will also vary as widely in their development and progress as typically developing children and each will have their own individual talents and aptitudes.
- Children with Down syndrome will all have learning difficulties, but these can vary from mild to very severe. At the age of five, the most able children are often functioning near the average level for their age. At the other end of the ability range, there are children with profound and multiple disabilities, often linked with conditions such as autism or epilepsy.
- While children with Down syndrome share certain physical characteristics, these will vary from child to child. Most importantly, each child will inherit its own family looks and characteristics.
- Although Down syndrome is caused by genetic factors, environmental influences and upbringing play a critical role in their development, as with any other child.
- As with many children, progress for those with Down syndrome is a continual but unsteady process, continuing into adulthood where the learning of new skills still goes on. The progress of people with Down syndrome does not decline with age, nor as was previously thought, do they plateau in their development.
- People with Down syndrome are living longer than ever before. The average life span, which has been increasing steadily over time, is now 60 years.

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c) Specific learning profile

Children with Down syndrome are not just developmentally delayed but have a specific learning profile with characteristic strengths and weakness. It is vital that this is recognised in order that the most appropriate strategies are used so that children with Down syndrome are able to develop their knowledge, learn new skills and be included into school as effectively as possible.

HOW DOWN SYNDROME AFFECTS LEARNING



Areas of strength – kinaesthetic and visual learners

- Strong visual awareness and visual learning skills.
- Ability to learn and use sign, gesture and visual support.
- Ability to learn and use the written word.
- Ability to learn from pictorial, concrete & practical materials.
- Keen to communicate and socialise with others.
- Tendency to model behaviour and attitudes from peers and adults.
- Structure & routine.

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Factors that inhibit learning

- Auditory and visual impairment.
- Delayed motor skills – fine and gross.
- Speech and language impairment.
- Short term and working memory weaknesses.
- Shorter concentration span.
- Difficulties with consolidation and retention.
- Difficulties with generalisation, thinking and reasoning.
- Sequencing difficulties.
- Avoidance strategies.

Visual and kinesthetic learners

Children with Down syndrome have a good visual memory and learn best from using visual and hands-on practical strategies and resources. This will involve the use of pictures, photographs, diagrams, symbols, matching strategies and ICT. In addition, as they have strengths in reading, print can become an excellent way to help them develop their speech and language, learn new information and access the curriculum.

Due to their poorer auditory (listening) skills, children with Down syndrome benefit from any verbal input being reinforced as visually as possible, which will include the written format. However, they also have strengths in learning from sign and gesture and from being able to read facial expression and body language.

Because many children with Down syndrome have a strong tendency to copy or mimic others, they learn well from mixing with typically developing peers. These act as good role models in terms of speech and language, set standards for appropriate behaviour and demonstrate new skills from which the child with Down syndrome can learn.

Motor skills

Generally speaking, the development of motor skills in many children with Down syndrome lags behind that of typically developing peers, and children reach their motor milestones later although still following typical development. This is particularly apparent in the early years and is partly due to poor muscle tone (hypotonia) and loose ligaments.

Sensory integration

However, research also highlights problems with processing and organising sensory information and coordinating movements. The motor-neuro pathways are less efficient and take longer to establish. This results in the pupil having particular difficulty learning motor skills e.g. writing, dressing and feeding, as their brain does not receive the appropriate feedback that is necessary to learn such skills.

Studies also show slower reaction times with difficulties in adapting movements. As a result, although muscles are able to perform the movements, they are often carried out in a slower, clumsier manner.

However, all motor skills improve with practice and given appropriate demonstration, practice and encouragement, most children will make slow but steady progress.

Gross motor skills

Problems with gross motor skills often improve by the time children reach the end of their primary education. However, many may still have difficulty coping with stairs or keeping pace with their peers in PE and games. Some children with Down syndrome

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dislike large team games, finding the level of noise and speed or pace overwhelming and the complexity of the rules confusing. They can also tire more easily.

Some children have particular problems with balance and spatial awareness or may be frightened of physical contact or being knocked over.

However, other children with Down syndrome enjoy this aspect of school life very much, so it is important not to deny them the positive opportunities for social participation that sport offers. Furthermore, as children with Down syndrome, generally have a slower metabolic rate than typically developing peers and burn calories at a slower rate resulting in a tendency to obesity, regular exercise is essential for their wellbeing.

Setting up small supported group activities in PE either for a mixed ability group or specifically geared towards children with additional needs, may be more appropriate as may be developing skills on a one-one basis.

Children with Down syndrome can also take longer to change but need to be encouraged to become as independent as possible and this could be a good target for many especially in the early years and KS1. Some pupils may need to leave the lesson early in order to change as independently as possible and still be ready for the next lesson.

Fine motor skills

Many children with Down syndrome have particular difficulties with fine motor skills. In addition to hypotonia, the fingers are often short and the thumb set low down. This, together with motor processing and sensory integration difficulties, affects their level of dexterity, manipulation and hand-eye coordination. These in turn affect their ability to hold and control a pen or pencil, use scissors or manipulate small objects. See Unit 6 for further information on developing fine motor skills.

Vision

Children with Down syndrome tend to be very good visual learners due to their good visual memory. However, many have more difficulties with vision than typically developing children and have poor focusing skills and reduced acuity (detailed vision). It is especially important that teachers as well as parents are aware of the visual difficulties that they may experience in order to provide appropriate compensatory strategies.

Long-sight, short-sight and astigmatism are much more common in children with Down syndrome. Typically developing children are often long or short-sighted in early infancy, but grow out of these errors over the first few years of life. Children with Down syndrome start out with a similar range of errors, but are much less likely to outgrow the errors and much more likely to become more long or short-sighted.

Children with Down syndrome have smaller noses and a shorter distance from ears to face than typical children, and so glasses have a tendency to slip down. This is not only irritating for the child, but means that he or she isn't looking through the correct part of the lens. It is important therefore, that they have glasses that fit properly and comfortably without slipping.

Regular eye examinations are important and those conducting eye tests must have specialist knowledge on vision related to children with Down Syndrome (Dr J. Margaret Woodhouse, Cardiff University).

Accommodation (focusing at near)

The greatest differences between vision in children with Down syndrome and typical children are found in their close or near vision and it is this vision that is needed so much in school or when children are following their interests e.g. reading or looking at a book, playing on the computer etc.

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Usually, children focus very easily and very accurately on near targets and it is only as we approach middle age that we expect to experience difficulty in focusing at near. However, most (over 70%) of children with Down syndrome focus very poorly at near – and tend to under accommodate by quite a large amount. This is consistent for any individual child, and persists even when the children wear their glasses to correct long sight. This means that near work, especially in school, must be more difficult for the children because it is out of focus.

Visual acuity

Research has shown that visual acuity (detail) is poorer in all children with Down syndrome than it is in typically developing children. Even if children wear bifocals successfully, or if they focus accurately without spectacles, their visual acuity will still be below normal. Thus reading materials, for example, do NOT look the same to a child with Down syndrome as they do to his/her classroom peers. The material does not appear to have the same level of detail. Enlarging the print may help the child to access print more easily, but does NOT restore a 'normal' appearance to the material.

Hearing impairment

Many children with Down syndrome experience some hearing loss, especially in the early years. Up to 20% may have a sensori-neural loss, caused by developmental defects in the ear and auditory nerves. Many have smaller sinuses and ear canals which result in frequent upper respiratory tract infections: this leads to over 50% suffering from periodic conductive hearing loss due to glue ear. Since hearing problems will affect speech and language development, it is particularly important to check children's hearing carefully and regularly. Also clarity in hearing can fluctuate daily and it is important to check that inconsistencies in response are due to hearing loss rather than lack of understanding or poor attitude. In addition, some children with Down syndrome have poorer auditory discrimination, meaning that they have greater difficulties recognising and discriminating between different speech sounds. This may have particular importance when teaching speech sound work and phonics for reading and spelling.

Speech, language and communication

Children with Down syndrome have a typical profile of communication skills and experience specific difficulties in developing spoken language over and above any language delay associated with their learning disability and hearing loss. However they are often very keen to communicate and in spite of their difficulties are able to use and learn from sign and gesture, the written word, pictures and symbols extremely effectively.

Generally speaking, their receptive skills are greater than their expressive skills. This means that they understand language better than they are able to speak it. As a result, their cognitive skills are often underestimated.

Any delay in learning to understand and use language however, will have an impact upon a child's level of knowledge and understanding and lead to cognitive delay. The ability to understand more abstract language and concepts will be particularly affected. Accessing the curriculum therefore, will inevitably pose more difficulties and can also affect their behaviour and confidence.

Many children have articulation difficulties and their speech can be hard for an unaccustomed listener to understand although your ear will tune in fairly quickly in many cases. The combination of having a smaller mouth cavity and weaker mouth and tongue muscles makes it harder to physically form words; and the longer the sentence, the greater the articulation problems become.

Children with Down syndrome respond to sign extremely well with many learning to sign words before they are able to speak. Signing acts as a bridge towards developing

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their language and communication and reduces frustration.

All early years settings who have a child with Down syndrome should seek training on signing from their local speech and language therapist.

Children with Down syndrome will need to be seen regularly by a Speech and Language Therapist who can suggest suitable activities and set a programme of work to be carried out within school by a Teaching Assistant (TA).

The typical speech and language profile affect a child's ability to:

- Understand language.
- Learn and remember words – vocabulary.
- Produce and use speech.
- Put words together into sentences.
- Understand longer sentences.
- Use and understand grammar – leaving out connecting words, prepositions etc. – resulting in a telegraphic style of speech.
- Make requests and talk about things that have happened.
- Have conversations and interact with peers.
- Use language to learn, sort out problems, deal with emotions.
- Put thoughts into words.

Short term auditory or memory working memory

This can be called the 'mental workplace' or gateway to learning and children with Down syndrome generally have poor short-term memory but good visual memory and long term memory.

Short-term auditory memory, also known as working or verbal memory, helps us to make sense of language. We use this memory to hold, process, understand and assimilate spoken language. It relates directly to the speed with which we can articulate words, and influences the speed at which children learn new words and learn to read.

Many theories about memory suggest that words we hear are received and stored in our working memory in order to make sense of them. They are then transferred to a more long-term store. However, words are only retained in the working memory for two seconds unless consciously kept there by silently repeating them to oneself, called rehearsing. The amount of information we can retain within the two-second span is called the auditory digit span. One way of measuring this digit span is to see how many digits, said at the rate of one per second, a child can repeat back. Words or nonsense words can also be used.

Typically developing children generally have a digit span of 3 words at ages 4/5 years, 7/8 words at 16 years. Young children with DS have significantly less than 1-2 words and teenagers with DS, will have digit span of about 3-4 words.

Working memory affects the ability to learn routines and develop organisational skills. It also plays an important role in developing language skills: in acquiring and retaining vocabulary (including phonic awareness and discrimination) and in understanding and producing language (including grammar and spoken and written language). Any deficit will therefore greatly affect a pupil's ability to respond to the spoken word or learn from a situation relying heavily on auditory skills.

Critically, learning from listening is difficult – words disappear too quickly from memory.

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A child struggling to process and remember what was said can quickly become overloaded if given unfamiliar vocabulary or long, complicated sentences. The child will either switch off completely or retain only parts, often from either the beginning or end of a sentence. This poses real problems for children in school situations with a high auditory content, such as:

- Carpet or circle time.
- Listening to a new story and whole class discussions.
- Assembly.
- Being given instructions.
- Hearing unfamiliar subject-specific vocabulary.
- Mental maths.

A child may have difficulties in:

- Processing and storing (remembering) information, especially when processing speech alone.
- Remembering new, unfamiliar or abstract vocabulary (poor learning of colours is typical).
- Phonological awareness: learning letters and letter sounds.
- Differentiating speech from environmental sounds: auditory discrimination.
- Remembering sequences or lists: these fade quickly if not rehearsed and used regularly.
- Understanding information they hear: auditory perception.
- Following long verbal instructions.
- Forming longer words and phrases.
- Developing reading, comprehension and grammar.

All speech and verbal information needs to be reinforced as visually and kinaesthetically as possible through additional resources and materials including sign, gesture, facial expression and body language where appropriate.

Concentration

Many children with Down syndrome have shorter attention and concentration spans than their typically developing peers. They tend to be more easily distracted and have difficulty focussing on more than one task at a time. Many may find it hard to cope with longer sessions. Others may be unable to concentrate if there is a high level of background noise or movement.

Where they are supported intensively on a one to one basis, they may become very tired and need a break.

In general, children with Down Syndrome benefit from a range of short, finite activities interspersed with short breaks.

Generalisation and transference of skills

Where any child has a speech and language impairment, thinking and reasoning skills are inevitably affected. As a result, children with Down syndrome can find it more difficult to make generalisations, to transfer skills from one situation to another or to make decisions and choices. They may well be able to perform a task in one situation but be unable to do so in a different situation and will need additional help to transfer the skill or generalise it.

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Consolidation

Children with Down syndrome generally take longer to learn and to consolidate new skills. Further, their ability to retain new learning can fluctuate from day to day. In addition, many are passive learners and the consolidation of new skills may be compromised by poor motivation, avoidance strategies or inconsistent performance.

Many children with Down syndrome are sensitive to failure and can, therefore, be unwilling to tackle new tasks. Some may have particular difficulty in correcting wrong responses once a mistake has been made and highlighted.

Research has shown that some children with Down syndrome tend to make poor use of acquired skills and in fact have higher levels of ability than they generally exhibit.

They need to be taught in a variety of ways with additional reinforcement and practice to enable them to consolidate new skills and knowledge.

The aims of inclusion

The vast majority of children with Down syndrome will benefit from placement in a local mainstream school, receiving their education alongside typically developing peers of their own age.

Research indicates that children with Down syndrome placed in the mainstream do at least as well if not better than children of similar ability in special schools.

Regular opportunities to learn, interact and play alongside typically developing peers gives children with Down syndrome the role models they will need to encourage them to develop age-appropriate behaviour.

Most children with Down syndrome have well developed visual and imitation skills and are also keen to join in with group activities. They are, therefore, likely to learn by copying other children. Putting children with Down syndrome with good role models is therefore essential.

Through play and social interaction in school, they can acquire the social skills required to interact appropriately with others and make and sustain relationships.

However they can also copy inappropriate behaviour, learning this quickly for its effect and the attention it can bring. It is thus important to ensure that whenever possible, children with Down syndrome are put with good role models. Often a child with Down syndrome is placed in a lower ability set or group due to the level of their learning. However if the child with Down syndrome will copy or become distracted by any inappropriate behaviour in the group, it may be more effective to place them in a group where the behaviour is more appropriate. If differentiation is needed wherever the child is placed, then it is important to look at the most appropriate group or setting in terms of good role models.

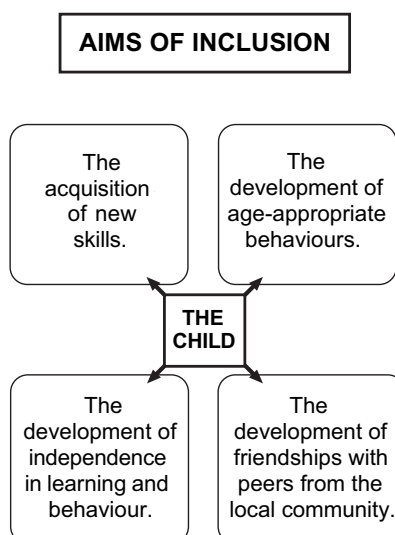
Placement in a school within their local community will also provide the opportunity to make friends with children they will see outside school.

While support may be required to facilitate learning, successful inclusion promotes independence. Although the demands of the curriculum may increase as the child gets older, they should progressively be more able to function as ordinary members of the school community, with help or support as and when needed.

Inclusive education benefits not only the child with Down syndrome, but also leads to greater understanding and less prejudice in the local community and ultimately in society at large.

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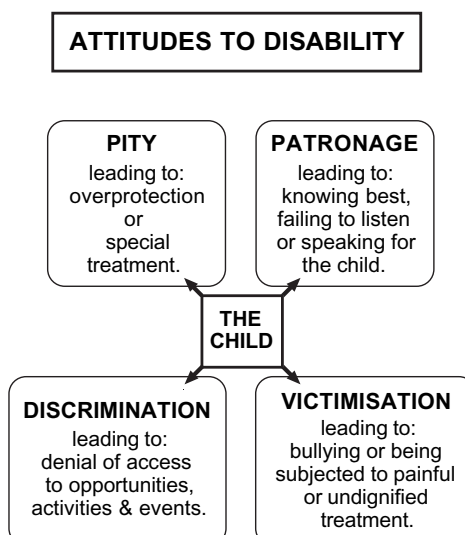
Children in inclusive schools learn to become more tolerant and patient and to support each other, rather than competing. They also learn to value diversity and to appreciate that everyone has something to bring to the life of the school.



d) Attitudes to disability

The Special Educational Needs and Disability Act (2001), which came into force in September 2002, makes it unlawful for educational providers to discriminate against disabled children by:

- Treating them less favourably than a non-disabled child on the grounds of their disability, without justification.
- Failing to take reasonable steps to ensure that they are not placed at a substantial disadvantage compared with other pupils who are not disabled.
- Failing to plan strategically for and make progress in improving the physical environment, increasing pupils' participation in the curriculum and improving ways in which written information provided to other pupils is also provided to disabled pupils.



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Staff working with children with Down syndrome need to be aware of and guard themselves against commonly held attitudes to disability.

Don't feel sorry for children with a learning disability and as a consequence give them special treatment.

Children do not 'suffer' from Down syndrome and special treatment will only serve to isolate them from their peers.

Always listen to the child, even if their primary form of communication is signing, gesture, body language or inappropriate behaviour. Don't think you always know what is best. Children who kick their teaching assistant are almost certainly unhappy about what she is trying to make them do.

Take care not to discriminate against the disabled children and deny them the same opportunities as others. Where there are difficulties in allowing a child to participate safely in an event or activity, share your worries with the parents and your colleagues so that a solution can be found.

Watch out for bullying or victimisation by staff or other students. Never tolerate name calling or teasing, as it is just as unpleasant and hurtful as racist or sexist language. Where the child clearly dislikes treatment or intervention being offered by an outside agency, discuss whether the programme is really necessary, can be adapted or if the same objectives could be achieved in a different way.

e) Useful reading

Alton, S. (2000) **Including Pupils with Down's syndrome**. Down's Syndrome Association.

Buckley, S. (2001) **Living with Down syndrome**. Down syndrome Issues & Information. DownsEd.

DfES. (2001) **Inclusive Schooling**. HMSO.

Selikovitz M. (1997) **Down syndrome: The Facts**. Oxford University Press.

Lorenz, S. (1998) **Children with Down's syndrome**. David Fulton Publishers.

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