

# Good practice guidelines for primary schools

This guide has been created for those practitioners working with children with Down syndrome in primary schools. We are keen to ensure that all such settings have the opportunity to have an understanding of Down syndrome, to have high expectations and understand the importance of language, and how best to help a child with Down syndrome to progress.

Development of speech for children with Down syndrome, is always delayed and so we advocate the use of Makaton or Signalong across the setting.



## What is Down syndrome?

Down syndrome, also known as Down's syndrome or Trisomy 21, is a naturally occurring genetic difference caused by an extra chromosome in a person's cells. Babies with Down syndrome are born in every country to parents of all ages, races, religions and backgrounds. Whilst the likelihood of having a baby with Down syndrome increases with a woman's age, the average age of a mother with a baby with Down syndrome is 29.

## How can Down syndrome affect a person?

Although people with Down syndrome share some common physical characteristics, a child with Down syndrome will look more like their family members than others who have the condition. People with Down syndrome are unique individuals with different personalities and abilities, just like everyone else. People with Down syndrome have some degree of learning disability which affects their ability to learn, it does not mean that they cannot learn. Children with Down syndrome may take longer to learn skills such as sitting, standing, walking, and talking, they will master them when they are ready and able.

## **Living with Down syndrome**

Like everyone else, children with Down syndrome are entitled to a place in mainstream education, and more young people with Down syndrome now leave home, have relationships, work and lead largely independent lives. Children and young people will receive support through their education and families are eligible to financial support.

## **Health and Wellbeing**

People with Down syndrome can be more prone to some common health conditions but, like the rest of society, benefit from medical advancements and subsequently live longer and healthier lives. In the 1960's life expectancy for someone with Down syndrome was 15 years of age, today this has risen to 60+ and increasing. Routine heart surgery means that those babies who require surgery generally do very well and are often home within a week.



# TALKING ABOUT DOWN SYNDROME

## Good practice guidelines

We cannot underestimate the importance and power of our words which reflect attitudes, beliefs and values.

It is vital to be factually accurate and inoffensive to people with Down syndrome, their families, friends and associates when speaking about any issue regarding Down syndrome.

An individual with Down syndrome is an individual first and foremost. The emphasis should be on the person, not the disability.

Always use person first language; if it is necessary to refer to the condition, say 'Jack has Down syndrome', never 'he's a Down's boy'. It is not necessary to constantly refer to someone as having Down syndrome. Please look at the person, not their genetic make-up!

Avoid the use of stereotypes and generalisations, eg "They are ...". Consider each child an individual as you would any other pupil.

Look at what a child needs rather than focussing on a problem, eg "Billy needs extra time to get changed for PE" rather than, "Billy has problems getting changed for PE".

Please describe people without disabilities as "typically developing" rather than "normal."

**People with Down syndrome are people who happen to have an extra chromosome, and have the same needs as everyone else - to be accepted, valued and respected.**

Avoid comments like, "You can't tell", "It doesn't look like they have it", "He doesn't have it that bad" or "My uncle's neighbour had one too." All are insensitive and derogatory and objectify an individual.

Avoid comments like "I can't believe how well he/she is doing" "She has Down syndrome but she's really pretty" or shock that "He won!". This is offensive to people with Down syndrome and those who love them as it implies an expectation that the person can't achieve, be pretty or win...

Comments like "It must be so hard", "I'm so sorry", "What a burden" are unhelpful. All parenting has it's good and bad times, these suggest life with a child with Down syndrome is always bad, which it most certainly isn't.



# COMMON MYTHS ABOUT DOWN SYNDROME

## **Myth: Individuals with Down syndrome are always happy.**

People with Down syndrome experience the same range of moods and emotions as everyone else in the population.

## **Myth: People with Down syndrome are all so friendly and loving.**

This is a gross generalisation about what “all” people with Down syndrome are like. The assumption that all people with Down syndrome are loving and want to hug can lead to the encouragement of inappropriate social behaviour. It can also lead to strangers behaving in a way that we would not accept for typically developing children unfamiliar to them.

## **Myth: People with Down syndrome suffer.**

Down syndrome is not a disease and people with Down syndrome do not ‘suffer’, people live with Down syndrome.

## **Myth: Children with Down syndrome should be educated in special schools.**

Inclusive education benefits not only the child with Down syndrome but also leads to greater understanding about difference and diversity resulting in less prejudice within the local community and ultimately in society at large. Research shows that children with Down syndrome do better academically and socially in inclusive settings.

## **Myth: People with Down syndrome all look the same.**

While children with Down syndrome share certain physical characteristics, these will vary from child to child. A person with Down syndrome will look more like his or her close family than someone else with the condition. He or she will also be most strongly influenced by their family and their lived experiences.



### **Myth: People with Down syndrome don't live very long.**

This myth comes from the past, however, the average life expectancy today is increasing with many people with Down syndrome living into their 60's and beyond. This is largely due to the advances in medicine, particularly the ability to detect and treat heart defects, and the changes in attitudes within the medical profession.

### **Myth: People with Down syndrome cannot read or write.**

In the past, the public perception of people with Down syndrome was that they were incapable of learning and therefore did not receive any sort of formal education. Now we know that people with Down syndrome are very capable of lifelong learning; many people with Down syndrome are visual learners so for them reading can be a particular strength.

### **Myth: Down syndrome is a spectrum.**

People either have Down syndrome or they do not, they do not therefore have it mild or more severe. In line with the general population, everyone with Down syndrome has a range of different strengths and weaknesses. It is estimated approx. 15% of children with Down syndrome will have autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD).

### **Myth: You can predict the future for someone with Down syndrome.**

No one knows the future for any child, a very small percentage will become brain surgeons or astronauts, the majority will lead ordinary lives and there are some people who will face various challenges. People with Down syndrome are no different—some will excel, the majority will lead full and rewarding lives, while others encounter challenges. As with all children, those born into caring families will be loved; families accept and adjust as they do with any family member who may need some extra support, time or effort.

### **Myth: People with Down syndrome cannot achieve normal life goals.**

Every year, more young people with Down syndrome than ever before are living in the community, gaining qualifications and experience as well as succeeding in a wide variety of jobs. People with Down syndrome date, socialise, form ongoing relationships, and get married.





# Toilet training



We collaborate with Bladder & Bowel UK to promote a 4-step training programme that recommends starting introducing the language around toileting, and regular sits on the potty from when the child is starting to sit, around 9 months old. Most children with Down syndrome can be out of nappies and in #Pants4School.

If working with children aged 5 and under, please [join our closed Facebook page](#) for more information and ensure you have high expectations around this life skill. For those working with children aged over kindly [join this closed Facebook page](#).

# LEARNING PROFILE OF A PERSON WITH DOWN SYNDROME

In general, children with Down syndrome develop more slowly than their peers, arriving at each stage of development at a later age and potentially 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.

There is a specific learning profile associated with the condition – a pattern of strengths and weaknesses. However, children with Down syndrome will vary as widely in their development and progress as typically developing children vary, and each will have their own individual talents and aptitudes.

Children with Down syndrome will all have some degree of learning difficulty. At the age of 5 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. Recent research suggests that between 15% and 20% of the population with Down syndrome are also on the autistic spectrum.

It is important that this specific learning profile is recognised in order that the most appropriate strategies are used so that children with Down syndrome can develop their knowledge, learn new skills and be included into school as effectively as possible.





## Specific learning profile

As educators, you will find this information about the specific learning profile of a child with Down syndrome interesting. This profile highlights the learning strengths and challenges that many of our children experience.

### The learning profile incorporates the following strengths and weaknesses:

#### Areas of strength:

- ▶ 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.
- ▶ Ability to learn and copy behaviour from peers and adults.
- ▶ Structure & routine

#### 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.

## FOR MORE INFORMATION

If you would like any further information about Down syndrome, please don't hesitate to contact us. There are also support groups across the UK who run a varied programme of training events through the year for professionals to understand more about working with children and young people with Down syndrome.

**Additional information and support can be accessed via our DSUK Primary Facebook group for professionals:**



**Links to further information  
about Down syndrome**

**[www.positiveaboutdownsyndrome.co.uk](http://www.positiveaboutdownsyndrome.co.uk)**

**[www.downsyndromeuk.co.uk](http://www.downsyndromeuk.co.uk)**

**[www.downsed.org](http://www.downsed.org)**

## Recommended videos to watch (YouTube)

**[Dear Future Mom](#)**

**[Stand Up For Downs - Help Us Shatter Stereotypes](#)**

**[Don't Limit Me](#)**

**[BBC Things People with Down's Syndrome Are Tired of Hearing](#)**

**[Chromosomes R Us](#)**

The best people to answer questions about Down syndrome are people with Down syndrome.



## Dear Future Teacher,

Hello, I'm Willow.

Please don't be afraid.

You're wondering how you'll meet my needs and help me to feel safe. You're wanting me to be happy in your class, and worried that I won't be. You're not sure how you're going to manage a class of 28 children and me. How will you cope with the workload? The extra resources? How will you manage any extra staff that may come with me? The inclusion? Getting it right for every child?

If you're thinking all this, then you're already doing an amazing job – so: thank you!

Please know, I come to you like any other child. I come to you with love in my heart and a joy for learning. I come to you hoping to be given the same opportunities as the rest of my class. Please don't limit my ability because you have a limited understanding of me. There's so much more to me than a diagnosis...

It may take me longer to understand some lessons, but in doing so, I'll help another child consolidate their learning when they want to help me. I will be the first to tell you that one of my friends is upset because one of my superpowers is being able to read people's emotions really well.



It may take me a little longer to get ready for break, but this may encourage compassion in my classmates as they help and teach me to zip up my jacket. I will be the first to greet you with a genuine smile in the morning and give you that heart-warming feeling that reminds you, through the tiredness and the long days, why you became a teacher.

It may take me longer to articulate my thoughts, and as I do, I am teaching our class patience, acceptance and respect. I will be the first to show you that pure determination and perseverance pay off. At times I will surprise you and the pride we will both feel when I achieve something will shine bright.

It may take me longer to write things down, and in doing so, I may teach you to be more creative in your delivery and remind you that each of your children learns in different ways and has different outcomes, not just me. I will be the first to teach our class that differences on the outside make no difference whatsoever; it's our insides that show true humanity, true love and true kindness. I'll be the one to teach people that we're more alike than different.

It may take me longer to run to the end of the finish line, and as I try my best, my classmates will show friendship and camaraderie as they cheer me on from the side lines and for some, maybe even by my side. I will be the one showing them that it's not always about being first, it's about being a good friend, a good person.

I will be the first to educate you, enlighten you and prove to you that Down Syndrome doesn't limit a person or their worth, because I will show you that I am so much more than a person who happens to have Down Syndrome. I am smart. I am funny. I am naughty. I am kind. I am thoughtful. I am valued so much by you.

Dear Future Teacher, my hope is that you see me first, and my diagnosis second. I hope you'll see all the good that comes with me. And the extra help you worried about organising – you'll soon find it is a great asset.

You will lead by example and show my classmates and your colleagues that I'm nothing to be feared. After all, who's afraid of a five-year-old?

I can't wait to be in your class!

Yours,

**WILLOW**

Written by Clare Fraser, mum to Willow

