



Living with Down syndrome

Sue Buckley

Overview

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Summary - People with Down syndrome, whatever their age, are people first. They are people with abilities, strengths and weaknesses like everyone else. They may have additional needs but first they have the same needs as everyone else of their age group. The quality of health care, education and community support provided to children and adults with Down syndrome makes a real difference to their progress throughout life. This module provides an introduction to all the issues that need to be addressed to enable individuals with Down syndrome, and their families, to enjoy full and happy lives within their communities. It offers an overview of the development of individuals with Down syndrome from infancy to adult life. It also provides a summary of the causes of Down syndrome, the incidence and prevalence of the condition, life expectancy and associated education and health care needs. Further modules in this series address each of these issues in detail.

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Dedication

This module is dedicated to my children, Roberta - who has Down syndrome, Lorna and Frank, all of whom have had a profound influence on my understanding of what it means to live with Down syndrome. Lorna and Frank have been best friends, supporters and advocates for Roberta since she was a baby.

Terminology

The term 'learning difficulty' is used through this module as it is the term currently in common use in the United Kingdom. The terms 'mental retardation', 'intellectual impairment', and 'developmental disability' are equivalent terms, used in other parts of the world.

Living with Down syndrome

People with Down syndrome can speak for themselves



"My name is Ruth Cromer. I live in Sydney near Bondi Beach with my parents and my brother. I am 26 years old. I have Trisomy 21. What is Down syndrome for me? When I was a school student, I went to normal schools (whatever they are!), and I was in regular classes. I liked my schools and I liked my teachers. I found the work hard, but Mum helped me with homework and my reading.

"They have always said that people with Down syndrome would not learn very much. When I was eleven years old, my teacher wrote in my report that 'We should not expect too much of Ruth'; but I want to show people that they are wrong about me having Down syndrome: I had that feeling inside me that I can do things.

"But I had to change schools as there was no help for me in the senior school. So when I was thirteen I had to start at a new school. I was a bit nervous at first. I did some classes with the other students doing English, textiles and dressmaking, and did special education classes. I wanted to learn to type, but the teacher said learning to type was too hard for me, but I did it anyway...

"So what was it like being a person with Down syndrome at school? I didn't have many friends in senior school, and sometimes I felt 'outside'. At lunch-time, I used to go to the school library and read books. When people were mean to me, I just walked away. And when some people were not interested in me, I felt left out. I felt lonely then. They were not friends of mine. And some people stared at me, and sort of pointed at me, and I found that rude.

"Having Down syndrome means it is hard to get a job. And when they do offer jobs they are not suitable, like the job at the airport, which was shift work ending at midnight! And then I would have to get home! How would I do it? But I had two office jobs, and I was the relief switchboard operator. But those jobs finished.

"But acting is the thing I wanted to do most and I have done it! I have worked as an actor on TV and on the stage. I started doing drama classes when I was 11 years old. So as an actor who happens to have Down syndrome I have been able to get lots of work! I have done videos promoting rights at work and in the community. And I perform at launches and promotions.

"I never thought I would be an actor on TV, but I was asked to be in 'A Country Practice' in a guest role. Then I got another job. I got a part in a play

on the stage. How did I get involved in it? Well, I auditioned and I got in...

"People always ask me how do I learn my lines? Do I have to have help? Well, I don't. I learn all of my lines myself and I keep at it. I also know the whole script. I never miss a cue. I do my job, and I work very hard. I am always ready on time, and I am very well organised..."

"What Down syndrome means to me is that I can have a life just like anyone else. And I have made a life for myself. I represent people with disabilities on three committees. I am a member of the management committee of the Down Syndrome Association of New South Wales. I do drama workshops at the National Institute of Dramatic Art with other actors who have intellectual disability. I do aerobics with my friends and swim with Dad every Sunday with the Bondi Mermaids in the ocean pool right through winter. Mum and I go shopping and we get to have lunch together. Sometimes we go to the art gallery, and we also do power walking several times a week. My brother Michael is cool and twenty-one. Nanna is dead now but I still love her. We had the best times together. I like to walk down and visit my grandfather on Sundays and have coffee with him. I write letters to my aunts and they write back to me..."

"I have learnt to be strong and can cope with people who are mean to me. I don't let it worry me, I forget it. I feel secure."

"But there are things that I cannot do. Michael stays out overnight. Why can't I? Michael goes away on weekends. Why can't I? I know why. Because I can't get there, and I can't drive a car, and my friends can't drive either."

"Now this kind of thing makes me mad. I went to the bank with my mother to open a cheque and key card account because I had a job and I was earning money. The lady in the bank kept asking Mum all the questions, and she didn't ask me anything! I felt like saying 'Hello! I'm over here, lady!'..."

"What is Down syndrome for me? I do not feel any different. I know it is there, but I do not think about it. I carry on with my life. It is not going to stop me having a flat one day and getting married. If my husband and I agree to have a support person to help us with the money, that's fine."

"I recommend that adults with Down syndrome need to be in the community a bit more. I strongly believe that our adults with Down syndrome can have a life. So what do you think about that!"

"In the play I did, my final speech is a powerful monologue, it really hits home: 'I have Down syndrome. It's not a disease. There is no cure. I was born that way. I don't like it, but I've learnt to cope with it. So have my parents. I'm not a disabled person. I'm a person with a disability. I'm a person first'." (Ruth Cromer, Australia)

Living with Down syndrome

People with Down syndrome are people first

Adults with Down syndrome are adults first, with the same social, emotional and achievement needs as other adults. They wish to live with privacy, independence, friends and partners, and to have a useful role in their community. They should have the same rights as other adults in their community.

Children with Down syndrome are children first, with the same social, emotional and learning needs as other children. They wish to be included in the world of childhood in their community and to learn and play with all the other children in the neighbourhood.



People first

- Individuals with Down syndrome are people first, with the same rights and needs as everyone else.
- The development of individuals with Down syndrome is influenced by the quality of care, education, and social experience offered to them, just like all other people.
- The daily lives of individuals with Down syndrome, whatever their age, are influenced by the resources available to them and the attitudes of the people they live with, the people they meet in the community and the people who support or teach them.



Babies with Down syndrome are babies first, with the same needs for love, security, warmth, and stimulation as all babies.

Elderly people with Down syndrome need the same care and support as all other elderly people in the community as they become more frail and their health needs increase.

"My Mum asked me the other day, 'How do you feel about having Down syndrome?' I said, 'Great. I feel good about myself'. She then asked me another question, 'What do you think people should know about Down syndrome?' I thought about that one for a while because there are lots of things to know, but the first thing is that I am a human being, who has the same feelings like everyone else. But the most important thing of all is that I like to be treated like every other member of the community." (Gabrielle Clark, Australia)



"My message to all of you is to keep your minds open to the idea that we should be able to make our own choices. If young people with Down syndrome are given opportunities to have many experiences in life, we will be better prepared to make decisions for ourselves. My advice to you is to encourage children and adults with Down syndrome with their dreams and goals and to believe that success comes from believing in ourselves." (Mitchell Levitz, USA)

People with Down syndrome should not be seen as different but rather as people who happen to have some additional needs. It is so important that this message is emphasised to all who work with children and adults with Down syndrome. They do have some special needs, which must be addressed with effective health care and education, but not in ways that exclude them from the ordinary learning and social opportunities that everyone else benefits from.

"When I was born, and the doctors told my mother I had Down syndrome, they told her I would never be able to do much of anything... I hope that in the future, doctors will tell parents of children who have Down syndrome to give them a chance to encourage them to be whatever they want to be." (John Taylor, USA)



The development of babies and children with Down syndrome is influenced by the quality of love, care, stimulation, education and social experience provided by their families and communities – just like all other children. Throughout this series, the authors will be providing information on how to meet the additional needs of individuals with Down syndrome but the need to see the person first cannot be over emphasised. If we only offered the child or adult without a disability the social and educational experiences that we have traditionally offered children and adults with Down syndrome, we would stunt development of those non-disabled individuals. It is clear that, until recently, we have been stunting the growth of individuals with Down syndrome in this way.

"I lived with Down syndrome all my life! The living part is great, but changing attitudes is tough going... I visualise a time when my friends and I are capable of choosing the right priorities and have the right skills to maintain employment and also be able to manage our own lives. We need your understanding and skills to do this. We need to be given the chance and time with priority of our dreams." (David McFarland, Canada)



A brighter future

In many countries, the lives of children and adults with Down syndrome are steadily improving. Advances in medical care, better understanding of the developmental and educational needs of children with Down syndrome and increasing social acceptance are providing greater opportunities to grow and learn, and to participate in society.

Many more children are attending inclusive schools with all the other children in the community and many more are learning to read, write and achieve academically than was the case even ten years ago. They are welcome in a wide range of clubs and leisure activities with their non-disabled peers.

Many more adults with Down syndrome are obtaining work, living independently, finding partners and marrying. The support that they need to achieve an ordinary adult life will vary. Some will need only minimal support from friends, neighbours and family (like the rest of the adult community) and some will need the full-time support of workers in disability services.

Over the last ten years, adults with Down syndrome in many countries have become effective advocates for themselves and for all with Down syndrome in their communities, by speaking in public, by lobbying politicians and by pressing for changes in education, improvements in vocational training and work opportunities, and a greater range of supported living options.

However, even in the more developed countries, many individuals with Down syndrome and their parents are still fighting for the right to be included in the community and in inclusive educational settings and, in some countries, they are still fighting for the right to have even basic health care and education.

All individuals

Everyone born with Down syndrome has an extra chromosome 21, (all or part of the extra chromosome). However, the effect that this extra genetic material has on an individual's development varies widely. It is not possible to predict the future development of a baby with Down syndrome from the diagnosis alone.

Some children have few additional health problems and some have serious health problems as a result of having Down syndrome. All individuals with Down syndrome experience some degree of learning disability. Some children progress within the lower ability range of the non-disabled children in ordinary schools, some children are more delayed, with moderate to severe learning difficulties, and a minority have additional, multiple difficulties leading to even slower progress. The development of individuals with Down syndrome does not reach a 'ceiling' or 'plateau' in adolescence. Like everyone else, they continue to learn into adult life and to grow as people, if given the opportunity to do so. The so-called 'ceiling' discussed in past literature was almost certainly the result of the lack of medical care and educational and social experience.

Individuals with Down syndrome have different personalities, they are not all placid, cuddly and musical – the stereotype that you may have heard about, which probably reflected the impoverished institutional lives of the past and the behaviours that were encouraged. Some individuals with Down syndrome are confident, extravert and enjoy lively social lives, some are very

Achieving more

- Learning to read and write
- Attending inclusive schools
- Finding a partner
- Participating in the community
- Working
- Living independently



All individuals

- Health care needs vary
- Developmental needs vary
- Educational needs vary
- Personalities vary
- Adult support needs vary
- Forget the stereotypes
- Down syndrome alone does not determine development

keen on sports and excel at swimming, gymnastics, water skiing or riding, others are quieter or even shy and prefer quiet pastimes with a few close friends.

Each child or adult with Down syndrome must be considered as an individual and his or her needs determined as an individual, taking account of the knowledge of the possible effects of Down syndrome on development, but not assuming that Down syndrome alone will determine development.



People with Down syndrome are not sufferers

"My name is Gabrielle Clark. I am nearly 19 and I have Down syndrome, I don't suffer from it as many people say, I just have it. I was born that way. My mother told me when I was very little that I had Down syndrome (Probably the day I was born, she's like that you know, always explaining the truth). I still don't understand completely what it means except that I have an extra chromosome and that I look a bit different and Oh yeah I'm supposed to be a bit slow, (My mum says I've never been slow in my life, but she's my mum and she's prejudiced)." (Gabrielle Clark, Australia)

Most individuals with Down syndrome and their families do not consider that they suffer from Down syndrome. Individuals with Down syndrome definitely do not like being described as sufferers. Children and adults live with Down syndrome. It has influenced their development but it does not cause daily suffering. Most children and adults with Down syndrome lead happy and ordinary lives, doing much the same things each day as the rest of the non-disabled community.



Labels matter

Words reflect attitudes, beliefs and values and they affect how children feel about themselves. Please remember to say

- 'Johnny has Down syndrome, not 'Johnny's a Downs'
- 'a child with Down syndrome' not 'a Downs child' or even worse, 'a Downs'
- 'Jenny has Down syndrome' not 'Jenny suffers from Down syndrome'

Labels matter

The words that we use to describe people convey powerful messages. If people with Down syndrome are people first and their development is not predictable purely on the basis of the diagnosis then it is very important that our everyday language reflects this knowledge.

It is important to always refer to the person first, that is, to always talk about a child with Down syndrome or an adult with Down syndrome if it is necessary to refer to the diagnosis, not a 'Down's child' or even worse 'a Downs' (as in 'We've got a Downs in our school', for example).



Children and adults with Down syndrome hear how we talk about them and it affects their self-image and self-esteem. If you had Down syndrome how would you like to hear yourself and the condition described? Please take a minute to reflect on this question.

The term Down syndrome is in common use because Dr. Langdon Down first described the condition. Traditionally, the term was "Down's syndrome" for many years but all English speaking countries except the UK have moved to Down syndrome in recent years, reasoning that Langdon Down neither had nor owned the condition so the possessive form is not appropriate.

Development is a dynamic, interactive and social process

For all children, development is a continuous and interactive process – it is not wholly determined by genes at birth. Genes may influence a child's ability to learn but they do not determine opportunities to learn. From birth, all babies are in a world where their relationships with those around them profoundly influence their development. Brain development is a highly complex, interactive process, which is affected by genes, other biological functions and learning experiences of all kinds. The structure and function of the brain after birth is profoundly influenced by input and activity.

Families matter

Those with most influence on the development of babies are their families. The quality of care, love and attention provided at home creates the first learning and growing opportunities for all children. Babies and children with Down syndrome, like all other children, benefit from loving and secure home environments, where they are played with, talked to and valued as family members. All children thrive in families that encourage their children to become independent and to behave in a socially acceptable manner right from infancy. All children thrive in families that praise and value all their children's achievements and where all family members care for and support one another.

In the past, families were advised to put their babies with Down syndrome into institutions and this still happens in some countries. However, the families of individuals with Down syndrome have been the main force for change in most countries, supporting one another and fighting for a change in attitudes, for appropriate services and for education for their children and young people.

Communities matter

The effects that a disability has on an individual are greatly influenced by the attitudes and opportunities of the community that he or she is living in. Until the last decade, most children with Down syndrome grew up in social and educational deprivation. They were not welcome at the same clubs, playgroups and social activities attended by other children of their age. They only mixed with children with similar or more severe disabilities in segregated settings. They were denied friendships with other people of similar age who were not disabled. They were not learning and growing within the world of children in their community. Imagine how social isolation and exclusion from school would affect the development of children without a disability and then consider its probable effect on the development of children with Down syndrome.

“What matters is that we develop as individuals, with the same right to live as anybody else as a human being and have a future of work with friends of the same age, whether ordinary or handicapped. What matters is that they may become a grown up woman or man and that when they finish work, they are able to go to parties or spend the night at friends, not to discriminate them for being as they are, that everyone listens to our voice, understand it and recognise our rights as citizens.

“Above all what I want to say, is that what matters most for me is that

Development is a dynamic, interactive and social process

- Development is not rigidly fixed by genes
- Brain development is influenced by input and activity from birth
- Families make a difference
- Communities make a difference
- Schools make a difference
- The Down syndrome community is making a difference



Environments matter

- Inclusion matters
 - in families
 - in schools
- Research has shown that children with Down syndrome growing up in families progress faster and achieve more than children growing up in institutions.
- Research shows that children with Down syndrome benefit considerably from inclusion in mainstream schools. Their spoken language skills and literacy skills are 2 - 3 years ahead.



See also:

- *The education of individuals with Down syndrome - An overview* [DSii-16-01]



people value what I think. I want to be happy with my parents and with my siblings but I also want to have my home and family, with Christian my boyfriend, built on our love. I have come to terms with my handicap, but I don't want to depend on my siblings when my parents are no longer with me. I work, I study and with my friends we will achieve a full life even though with some support. Handicapped people need help to carry on - not everyone understands this. I have always said that people who laugh at people who are handicapped, are much more handicapped than us. I would like to finish by saying that it doesn't matter to have Down syndrome, it matters to be alive, to feel and to hope like everyone else. It is true that we need help to carry on and fight in order to enjoy life, but the challenge is worth it." (Mariana Paez, Argentina)

Fortunately, social attitudes have been steadily changing in most countries and children and adults with Down syndrome are being more fully included in the social worlds of their communities.

Schools matter

Children with Down syndrome did not go to school in most countries until some 25 to 30 years ago. At this time, many 'developed' countries started to provide access to special segregated schools, with only other children with disabilities in them. Most of these segregated schools focused on only teaching practical skills to assist everyday living, assuming that no child with Down syndrome could learn to read and therefore offering little or no academic curriculum. A school that only takes children with significant disabilities creates an abnormal and impoverished social and learning environment. The children, as a result of their disabilities, usually have very delayed speech, play and social behaviour. They cannot help one another and there are no age appropriate models to help them to learn to talk, to show them how to play or to model age appropriate behaviour.

"I'm sorry I didn't have inclusion when I was in school. To get my good education, because they didn't have any good classes in my neighbourhood, I had to travel on a bus to a faraway district. So I didn't know anybody in my own home town. If I could go back in time and do it again, I would prefer to go to school in my own town so I could have gotten to know some local kids." (Jason Kingsley, USA)

In many countries around the world, children with Down syndrome are still excluded in this way, or do not have access to any formal education.

In some places, educational opportunities have started to change in recent years. Early services and education programmes have been made available from infancy. More and more children with Down syndrome have had the opportunity to attend mainstream schools with their typically developing peers. More adults are gaining increasing independence and opportunities to work.

The studies of the progress of children with Down syndrome in inclusive educational settings all indicate that the children benefit and that they achieve higher levels of literacy, numeracy and academic attainments than children in segregated educational settings. The evidence also suggests that the children with Down syndrome included in mainstream schools with their typically developing peers have considerably better spoken language skills and more mature social skills than those in special schools. These research studies have not been able to find any disadvantages of mainstream inclusion, providing the young person with a disability really is socially

included. They found no evidence for actual benefits of segregated special education.

Despite increasing evidence of the benefits of inclusive education, even in countries where access to education in an inclusive setting is supposedly available as a legal right, it is not always easy to obtain and parents may still have to fight for a place for their child.

“From age 3 to the age of 7, I went to a parish school near my home. One day I asked my mother why the children in my class were aged 4 and I was the only one aged 5, and she told me that I had a problem that made learning more difficult, but she said that children are all different and learn if they make the effort. Then I went to special school where I learned to read and many other things. I learned to help children who have more problems than I. When I was 11 years old, my teachers and my parents decided that I was ready to go to a regular school. It was a very large school and there were 30 in the class. Most of them were 2 years younger than I, and I stayed there until I was 17.

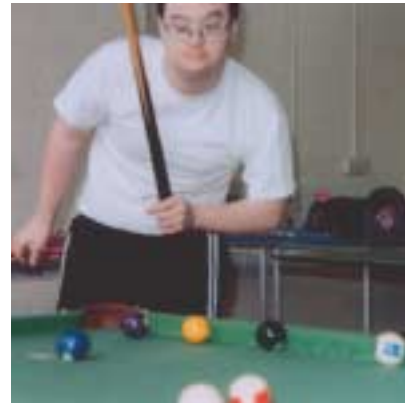
“In those 6 years, I learned many things. I have made my education work. The effort has been worthwhile for myself and for other people. Each one of us with our own differences, can find a place in the world. What I disliked most, was leaving the class for individual support and what I liked best was history, which has always interested me very much. I was very lucky with my friends, and I learned a lot from them and they always treat me like one of them, and I cannot forget my teachers who helped me very much. At home, they treat me the same as my brother and sister and I quarrel quite often with my sister who is quite near me in age!

“One day I was asked what I felt when I discovered that I had Down syndrome. At first, I did not like to know this, or at least I should have been told when I asked my mother why my class mates were two years younger than me. They took a long time to tell me. This is something my friends complain of regarding their parents, also. I should have preferred to know sooner. I should like to ask all the parents of children with Down syndrome not to worry and have confidence in us. We need the confidence in order to progress, because we are like everyone else. Although we have Down syndrome, this does not mean that we do not feel the same as any other normal person. I have never given any importance to the Down syndrome of my friends. I have always wanted to help those that need help. To finish, I would like to ask teachers to give a lot of importance to our education, and parents, that they have confidence in us.”
(Andy Trias, Spain)

The Down syndrome community

Over the last 20 years, an international community of people and organisations concerned to support those with Down syndrome has developed. This is a community of people with Down syndrome and their parents, of practitioners who provide services including doctors, teachers, psychologists, speech and language therapists, physiotherapists, social and community workers, and of researchers who try to understand the effects of Down syndrome on all aspects of development and to design and evaluate effective interventions and services.

Down syndrome associations exist in many countries and regions, usually organised by parents and by people with Down syndrome, and these are a great source of support for individuals and families and a great force for change in their countries. Often researchers and practitioners are also involved in these associations. An increasing number of national and international conferences and meetings are held, enabling people to share expe-





rience and knowledge. Every three or four years the international Down syndrome community holds a World Congress. The 7th World Congress was held in Sydney in March 2000 and the 8th World Congress will be held in Singapore in November 2003. The proceedings of the Congress are usually published as a book, enabling the new knowledge presented at the Congress to be shared with all who influence the lives of children and adults with Down syndrome.

Key facts about Down syndrome

Key facts about Down syndrome are summarised in the next section. Each of the issues is discussed in more depth in the other modules in this series.

Down syndrome is a chromosome disorder

Down syndrome is caused by the presence of an extra chromosome 21 in either the sperm or the egg cell. Chromosome 21 is the smallest of the human chromosomes and contains about 225 genes. The majority of children with Down syndrome (95%) have trisomy 21 (an extra chromosome 21 in all their cells), some 3-4% have a translocation form of the extra chromosome (where the extra chromosome 21 is attached to one of a different chromosome pair) and about 1-2% are mosaic (only some cells are trisomic, the rest are normal). However, the type of chromosome pattern does not significantly alter the pattern of learning difficulties that usually accompany Down syndrome. Children with the mosaic form may be less delayed in some areas of development but seem to experience a similar profile of language and learning difficulties.

Anyone can have a baby with Down syndrome

Children with Down syndrome are born at the same rate to parents of all social and educational levels, in all ethnic groups and to parents of all ages. Although the risk of having a child with Down syndrome increases with maternal age, a baby with Down syndrome can be born to a mother of any age. The risk is about 1 in 2000 at 20 years of age and 1 in 45 at 45 years of age. However, as the number of babies born to younger mothers is much higher than the number born to older mothers, most babies with Down syndrome are born to mothers under 35.

Down syndrome is identified at birth

The child's disability is almost always recognised at birth and parents are able to find parent support groups in many countries. Most children with Down syndrome in the UK will receive early home-based education and therapy and parents are used to being involved in their child's educational progress from the first year of life. Parents of children with Down syndrome in many countries have advocated effectively for an increase in inclusive preschool or nursery provision for their children over the last 10-15 years. Some countries have better services than the UK and longer experience of early education programmes and inclusion in education but in most countries around the world, the services available to children with Down syndrome and their families will be minimal. In many countries, families lack access to even basic information about Down syndrome, but in most countries around the world, parent-led associations are beginning to grow and create change.

Key facts about Down syndrome

- Down syndrome is a chromosome disorder
- Anyone can have a baby with Down syndrome
- Down syndrome is identified at birth
- Down syndrome is a common condition
- People with Down syndrome have long lives
- There is a wide range of individual needs and abilities
- Development continues throughout life
- Down syndrome is not a degenerative disorder
- There are effective interventions, but no known treatments or cures for Down syndrome

Screening for Down syndrome

At the present time, it is not possible to determine who is at risk of having a baby with Down syndrome before conception, other than the risks associated with increased maternal age. The presence of Down syndrome can, however, be detected during pregnancy. In some countries blood tests, which can be used to try to predict the probability that the baby has Down syndrome, are offered to all pregnant mothers. This test is used to advise parents of risk and to indicate risk to those who might wish to have an amniocentesis, the accurate way of determining the presence of the extra chromosome. A positive diagnosis from amniocentesis (when fluid from around the baby that contains foetal cells is collected by inserting a needle into the womb) may lead to the offer of termination at 16 to 20 weeks of pregnancy in some countries.

The blood test does not detect all babies with Down syndrome, and it falsely indicates risk to many parents whose babies do not have Down syndrome (about 43 out of 44 'at risk' predictions leading to amniocentesis are false positives, i.e. only 1 in 44 actually has Down syndrome). There are also some signs that can be seen on an ultrasound scan, such as heart abnormalities or an unusual area at the back of the neck (nuchal fold), and these signs may also lead to the offer of amniocentesis to parents.

Ethically this is a very difficult area and the author personally does not believe that the diagnosis of Down syndrome should justify termination. Most families recover from the shock of diagnosis surprisingly quickly after the birth and love their child with Down syndrome just as they do their other children. Children with Down syndrome and their brothers and sisters lead happy and fulfilled lives, with no evidence that growing up with a child with a disability is having long-term detrimental effects. On the contrary, many family members, parents and brothers and sisters can identify ways in which they benefited, while being realistic about the extra demands they had to meet. Some families (about 15%) have more difficulties and do not find it so easy to cope, especially if their child has more severe delays than are typical, has behaviour problems or has additional illness. It is also not so easy to cope if poverty, unemployment or poor housing are adding to family stress. These families can be identified and should be a priority for support from parent groups and services.

However, decisions about termination are a personal matter. An alternative choice to termination, for parents who feel that they will not be able to meet the needs of their baby with Down syndrome, is adoption. In many countries, the number of families willing to adopt a baby with Down syndrome exceeds the number of babies available.

Down syndrome is a common condition

Down syndrome is the single most common cause of moderate to severe learning disability in childhood. It occurs at the rate of about 1 in 700 to 900 live births, depending on screening and termination policies in different countries. There are currently estimated to be some 30,000 individuals with Down syndrome in the UK, a country with a total population of almost 60 million.

Screening is not reducing the population, in the UK or elsewhere, as dramatically as predicted. Health care is increasing survival rates in infancy and the



Life-long learning

- People with Down syndrome learn throughout life.
- Adolescence and early adulthood are often times of considerable progress.
- People with Down syndrome are responsible citizens.



population of school-aged children with Down syndrome is still increasing in the UK. It is expected to continue to do so into the next decade. The number of children with Down syndrome of school age (5 to 19 years) in the UK is estimated to be between 8000 and 9000 children.

People with Down syndrome have long lives

This is clearly a significant population of individuals and, as their life expectancy is now 45 to 55 years with some living beyond 60 and even 70 years, it is important that these children benefit from educational opportunities that equip them for useful and semi-independent adult lives in the community. With appropriate education, training and support some 60-70% of adults with Down syndrome could find some form of employment. This statement is not an exaggeration; it is not just the most able minority who can be independent.

For example, the author's daughter with Down syndrome, Roberta, left school with no reading skills at all, unable to count and unable to even name all the coins and notes of our currency. Roberta was born in 1969 and had a disrupted early life. She spent her first 16 months in an institution before being adopted into our family. She did not walk independently until she was 4½ years or say a single word until she was 5 years old. She certainly made a slow start. Now, aged 31 years, she lives in supported housing in the community, draws her own money at the bank, pays her own rent and chooses how she will spend the rest of her money, which she keeps in a building society account. Roberta makes her own decisions about how she will spend her time. She takes care of her own personal needs and laundry, she attends some adult education classes at college and is still improving her literacy and money skills. With her friends, she enjoys various activities in the local community – some for people with special needs, others the ones that you and I go to, and she has part-time work for which she is paid the UK statutory minimum wage.

I now reflect on the fact that, when she was a child, I overestimated the effect that lack of academic skills would have on her adult life and I undervalued her social skills, her good social behaviour, her confidence and enthusiasm for social participation. I also observe that Roberta and her friends with disabilities are competent and socially responsible members of their community. They use all the local social amenities independently (without a support worker). They go to the pub, but do not drink too much and become drunk and disorderly. They go to the local shops and cafes. To my knowledge none of them has ever stolen or created a public nuisance. They do not get into trouble with the law.

Roberta never gets into debt, despite having little money. She takes care of her money and saves it for clothes and holidays of her choice. I am also struck by the way that Roberta and her friends take care of one another and support each other through difficult times, illness and bereavements. In other words, the levels of social competence and social sensitivity that Roberta and her friends with learning disabilities display in their everyday lives are considerably better than those displayed by so many supposedly intelligent and better educated members of our communities.

The older Roberta becomes, the more I see the likenesses between her and her brother and sister in important life skills and needs, and the less I see the differences. I wish that I had had a vision of the competent adult

that she could become when she was a baby, rather than the vision of eternal childhood and dependency that I was given. I would then have been able to be a better parent for Roberta.

There is a wide range of individual needs and abilities

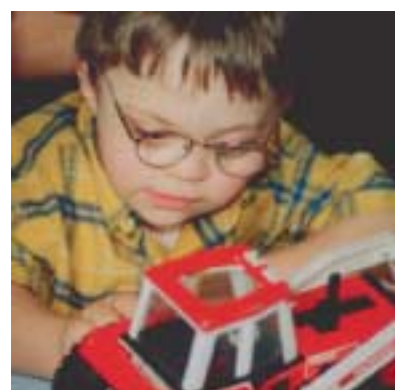
No two people with Down syndrome are the same, any more than any other two people are the same. Although each person with Down syndrome has the extra chromosome 21 in their cells from the time of conception, the effect on physical and mental development still varies widely, in ways that cannot be explained at present. For example, about half of all children born with Down syndrome have congenital heart defects (the development of the heart is affected during foetal development) and the rest of the children are born with normal hearts.

Many children with Down syndrome have hearing difficulties at times but some never have hearing difficulties. Many need to wear glasses to correct their vision, but some do not.

The effect on motor development, learning ability and mental development is also varied. Most children with Down syndrome are floppy at birth (described as hypotonia) but some continue to be 'floppy' and need extra exercise, others do not.

Most children and young people with Down syndrome learn and progress more slowly than most children without a disability, but some are only mildly delayed and some severely delayed. Some children learn to speak more slowly but quite clearly, others have great difficulty developing clear speech. Some children with Down syndrome can learn to read as well as other children in their mainstream classes, other children with Down syndrome will not manage to learn to read at all.

Most adults with Down syndrome are able to lead quite ordinary lives in the community, shopping, working, going to colleges and to clubs with minimal support, often living in supported housing. Others (about 15%) need a much higher level of daily assistance with care and activities.





The diagnosis of Down syndrome cannot tell you how a child or adult will progress. It can tell us that there are certain health and learning difficulties which are found more often in individuals with Down syndrome than in other individuals, and alert us to the need to assess the health care and educational needs of the individual child or adult with these added risks in mind.

Intellectual or mental abilities

In the past, the intellectual or mental development of children and adults with Down syndrome has often been described in terms of IQ (Intelligence Quotient) calculated on the basis of the individual's performance on an IQ test. The majority of research studies into the mental development of individuals with Down syndrome have used this type of measure.



However, IQ tests have limited practical value. They tell us little, if anything, about the speech and language skills of an individual, whether or not he or she can read to a level that is useful, make a meal, use public transport or behave in a kind and socially appropriate way.

For this reason, many practitioners who provide services or education prefer to measure the progress of children and adults in each of the separate skill areas that are relevant for daily life.



When we do this it becomes clear that the development of children with Down syndrome is not equally delayed in all areas. While progress in all areas is usually slower than it is for typically developing children, the social and emotional development of children with Down syndrome is a strength and only slightly delayed in infancy. The social skills and empathy shown by children and adults are usually a strength throughout life. Motor skills are delayed and interfere with the ability to play and explore but motor, self-help and social skills are usually ahead of speech and language skills by school age.

Speech and language development is an area of particular difficulty for children with Down syndrome, and the children's speech and language progress usually lags behind their non-verbal reasoning and communication abilities. This is very frustrating for them and poor spoken language skills adversely affect all aspects of their lives. Fortunately, research is beginning to provide some clues to the reasons for their speech and language delays and to provide guidelines for effective interventions. Two of the difficulties that delay spoken language are speech-motor difficulties, which delay the ability to

produce recognisable speech sounds and words, and poor auditory short-term memory function. Activities to improve speech sound production and memory skills can be effective from early childhood and probably still into adult life.

We also know that individuals with Down syndrome are visual learners, that is, they learn more easily from visual than spoken information and the use of signing and reading are proving effective in improving the speech and language progress of children and of adults with Down syndrome. Signing can be introduced in infancy and reading can be an effective means of teaching language from as early as 2 years of age. As learning to talk underpins the other important mental abilities of thinking, remembering, reasoning and learning, if we can accelerate the speech and language development of children with Down syndrome, we can improve their mental abilities and the rate at which they can learn.

Development continues through adult life

There is no evidence to support the view that children with Down syndrome reach some ceiling in learning by adolescence and do not go beyond it. Studies following children over time have disproved this myth.

People with Down syndrome continue to develop reading and writing, speech and language, independence and social skills into adult life. Indeed the author's daughter with Down syndrome, Roberta, made quite dramatic progress between the ages of 22 and 31 years thanks to a move to independent supported living and to falling in love.

The move to independent living gave Roberta the chance to be an ordinary young woman in the community, taking charge of her own life and doing ordinary things each day (cleaning, washing, shopping, drawing money at the bank, paying bills, going to college classes, supported work, going to the pub, the cinema, the bowling alley) for the first time in her life. Until then, Roberta had attended special segregated schools from the age of four years, special segregated further education and special segregated day services. Each weekday morning she would catch a special bus to a special place with only other people with disabilities for company. Her brother and sister would go to school together with their (and Roberta's) neighbourhood friends. Imagine how that made Roberta feel, day after day from four years of age. She was certainly being told by us all that she was different and that she and her disabled friends did not belong with other children. Imagine the effect on her self-image, her self-identity, her understanding of her place in the world – who she was and how we all regarded her. I include us, her family in this, because although we suffered much heartache, knowing the negative effects of these segregated services for Roberta, we still sent her to them, having no alternatives available in our community at that time despite fighting for them. So from Roberta's viewpoint we were colluding with the rest of society and saying 'This is OK for you', simply by sending her off to the bus each day.

In the first year of independent living, we watched Roberta's skills and self confidence grow rapidly, thanks to the support of a young team of support workers who treated her with respect and treated her as an adult

Development continues in adult life, influenced by attitudes and opportunities

- No one stops growing, developing and learning new skills when they become adults or leave school.
- Life circumstances can support, prevent or suffocate growth and development.





who could and should take charge of her own life. During this year, Roberta met and fell in love with Michael, a young man living nearby and the effect for both of them was wonderful to watch. Michael also happens to have Down syndrome.

Not only did they adore each other and wish to spend all their time together, like all other lovers, they also opened up each others social lives and showed us just how much we had underestimated Roberta. We realised then, how much her progress had been stunted by the lack of opportunities and low expectations of those paid to teach and support her for so many years. First, Michael could use the buses, a skill Roberta had not yet achieved, and so her social life was transformed as they could go off to town together. Roberta is the eldest and has a brother and sister close in age, so she was used to going to the cinema, the pub, the bowling alley or the burger bar. She knew how to use all these places once she was there but lacked the independent travel skills. Michael is the youngest of a large family and some 13 years older than Roberta. He did not have the same social experience so they made the perfect match. Michael could get them to town and Roberta knew what to do when they got there!

Roberta quickly began to surprise me with her ability to plan ahead and organise things. For example, three weeks before Michael's birthday I called at Roberta's house. She immediately took me to one side and explained that Michael's birthday was coming and she wanted to take him to a new six-screen cinema on an out of town leisure complex and then have supper in a nearby restaurant that her brother was managing at this time. Roberta had clearly thought this through and remembered that this leisure complex was not on a bus route. If she was going to take Michael there on his birthday, then she needed me with the car to get them there. At this point in Roberta's life, I had no idea that she could plan and solve problems like this and I felt very sad because I realised that she had never had any reason to want to show this ability until she met Michael. We had never created the right circumstances – until she met Michael she could only travel on an outing if we organised it or people paid to be with her organised it. We had all encouraged passive acceptance. In fact, when Roberta was a teenager I was aware and worrying about this, but did not solve it. For example, one evening I was talking to her about a school trip she was going on to somewhere new the next day and she just said to me as I talked about what she had to do: "It's alright Mum, staff 'll tell me...", in other words, "I don't need to think,

just do as I am told". We, the adults around her, were teaching her 'learned helplessness' and conformity. In Roberta's life, until she left home, she had learned that she had no choices, only one school to go to, only one adult day service ... so even if you didn't like it, you put up with it.

As Roberta continued to experience her new life, with freedom to make her own decisions, an increasing ability to take care of her daily needs, and the love and support of Michael, we watched her self-esteem and her self-identity change. I cannot know because Roberta could not express herself in terms to enable us to really discuss it, but I feel sure that she now sees herself differently from the way she saw herself ten years ago. She is now a young woman leading a life much like other young women her age who have limited education and employment prospects. I think she now sees herself as much like other people her age rather than different and dependent – she has the same things, her own home away from her parental home, a boyfriend, friends and her own life. This was not what her childhood experience prepared her for or led her to expect. She blossomed and surprised us all once the community let her be an ordinary person. She blossomed also because she was loved and had that special relationship with another person that is so central to most of us as adults.

Michael and Roberta shared a fully adult relationship, in which shared sexuality, caring and physical closeness was as important as it is in all successful partnerships. I was thrilled for them and delighted at the positive effects the relationship was having for them both. Here again, Roberta found herself leading a normal adult life, with a lover like most others her age.

Unfortunately, this story is not a fairy tale and it does not have a 'they lived happily ever after ending'. Michael's family did not share our positive view of this relationship and their disapproval eventually (after six years) proved too much for Roberta and Michael to deal with. However, like all life experiences, Roberta is older, wiser and an infinitely more adult and capable person as a result of both the joys and pains of the experience. She and Michael are still friends but I am sad at the loss for them of what I believe would have been a lifelong partnership.

Down syndrome is not a degenerative disorder

It is sometimes suggested that Down syndrome is a degenerative disorder. Often, this is concluded on the basis of IQ scores and limited observations from brain studies. However, this is definitely not the case. The first observable effects of a degenerative disorder in children are a slowing down of progress, followed by cessation of development and eventually the loss of previously acquired skills.

Children with Down syndrome do progress more slowly in all areas of development but they do steadily progress and continually learn more skills, unless they have some other illness, in addition to having Down syndrome.

Understanding decline in IQ

Intelligence tests have been used for many years to assess children's mental abilities. They are standardised tests containing a range of subtests intended to measure different aspects of children's knowledge, memory and reasoning abilities. The subtests tend to focus on measuring those abilities that show rapid change year by year. The standardisation data allows testers to compare the scores for a particular child with those of a large sample of

Self-identity and self-esteem matter

- Self-identity and self-esteem are socially created, they reflect the way we are treated by others. We learn to understand who we are and what we are good at in social contexts.
- Special school and special services segregate disabled people.
- We learn that we are different and do not belong when away from brothers and sisters.



Down syndrome is not a degenerative disorder

- Children with Down syndrome make steady progress in all areas of development.
- There are no 'cures' or 'treatments' for Down syndrome at the present time.
- But development is influenced by loving parents, effective therapy, inclusive education and caring communities.



children of the same age, so that they can see if the child is doing better or worse than the average of this large, representative sample. While intelligence tests are now recognised to have limited value in any assessment of a child's educational needs, they have been widely used in research studies. Mental Age scores are obtained by finding the age at which an average child would achieve the tested child's score on the test. If the child's Mental Age is the same as his or her chronological age, he or she will have an IQ of 100. If Mental Age is below chronological age, the child will have an IQ score of less than 100.

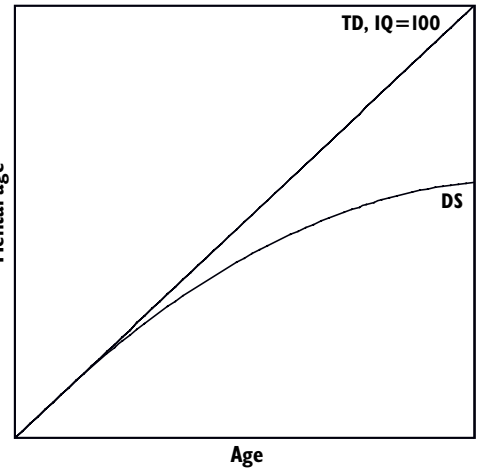


Figure 1. The relationship between age and mental age for typically developing (TD) children and children with Down syndrome (DS)

In many studies of children with Down syndrome, IQ results are reported and almost always show that the children's IQ scores decline as they grow older. Babies with Down syndrome attain higher scores in infancy and then their scores tend to go down each year though this decline stops by the end of primary school years. While this fact is not in dispute, it is frequently misinterpreted as suggesting that their actual ability declines with age. In fact, the children's actual scores on the test items show steady improvement each year. They are making continuous progress, learning more and acquiring new skills each year. However, they are progressing at a slower rate than the ordinary children they are being compared with each year. This means that their standardised IQ score becomes lower each year, as it calculated by comparison with the progress of typically developing children of the same age, even though they are making steady progress and their Mental Age scores are increasing.

Therefore, decline in the IQ scores of children with Down syndrome does not mean a loss of skills or arrest of development at all. One of the reasons for the decline in IQ scores is the very slow development of speech and language for most of the children and some early intervention programmes have reported success in slowing or stopping the IQ decline.

Differences in brain development

There are many studies describing differences in the early brain development of infants with Down syndrome, but the way in which these changes may influence the development of functional skills and learning is not known. Difference does not mean degeneration. The brain is developing and increasing in function as the behavioural progress of the children shows. It may be developing in the best way that it can, given the effects of the extra chromosome 21 in every cell. Very many aspects of the structure and physiology of the body are affected by having Down syndrome and the significance of some of the differences seen may be being misinterpreted if simply compared with the developing structure and physiology of infants without the extra chromosome. Efforts to return the physiology of the Down syndrome child to

'normal' with 'drugs' or 'supplements', without scientific evaluation of the outcomes, may be equally misleading.

There are effective interventions but no known 'treatments' for Down syndrome

Currently there are extensive research efforts in progress around the world in an attempt to understand the effects of the extra genetic material, which may eventually lead to pharmacological treatments that improve the rate of development and health of individuals with Down syndrome.

At present, there are no known pharmacological or 'nutritional' treatments that have been shown to have any effect on the developmental progress of children with Down syndrome, even though some such 'treatments' are being aggressively promoted in some places. The current ones are often described as 'Targeted Nutritional Interventions' (TNI). Sadly, there is no credible evidence of either safety or effectiveness of these treatments and some proponents play on the anxieties of parents seeking to do the best for their child with Down syndrome at a time when they are at their most vulnerable, suggesting that without such 'treatments' their child's condition will deteriorate. Frequently, these 'treatments' will be promoted with so-called supporting evidence and 'scientific' rationale which, although superficially appearing to be technical and authoritative, are in fact inaccurate and misleading. At the present time, we can make a difference to the progress of infants with Down syndrome, and to their brain development, with effective healthcare, educational and developmental interventions, starting in the first year of life. At the present time, we cannot 'treat' Down syndrome with pills.



The additional needs of people with Down syndrome

Additional healthcare needs

Babies and children with Down syndrome are at greater risk of a number of childhood illnesses and disorders. All these illnesses are seen in other children, but are seen more frequently in children with Down syndrome. All these treatments are treated in the same way in children with Down syndrome as they are in other children. Here we list the most common additional healthcare needs to ensure that parents, carers and physicians are aware of them.

Childhood

Babies with Down syndrome are at greater risk of having some congenital disorders. Some 40% of babies are born with serious congenital heart defects, but most can now be repaired by heart surgery during the first year or improve with time. A smaller number of babies have intestinal obstructions, which require surgery shortly after birth. Babies with Down syndrome tend to be less resistant to infections and need extra care during infancy and throughout life. They are also at greater risk for thyroid disorders and some other illnesses, most of which are easily treated.

All babies will benefit from being in the care of a paediatrician from birth, who is familiar with the specific health risks associated with Down syndrome. Health care guidelines have been developed in several countries to

Health issues

- Increased risks of:
- Heart abnormalities
 - Infections
 - Underactive thyroid
 - Conductive hearing loss
 - Visual impairment
 - Leukaemia during first 5 years
 - Dementia during later life (over 40 years)



Preventive medical care

- Paediatric healthcare in infancy.
- Screening for cardiac abnormality in infancy.
- Regular screening and care for hearing and vision.
- Regular screening for thyroid function.



ensure that parents and general physicians are fully informed of the special needs of children and adults with Down syndrome.

Later life

By the time they reach their teenage years, most young people with Down syndrome are healthy and have similar healthcare needs to the rest of the population.

In middle to old age (beyond 40 years of age), adults with Down syndrome are at greater risk of developing the dementing disorder Alzheimer disease. It is important to seek a proper diagnosis, and not just assume that a change in mood or initiative means dementia is developing, as these could be symptoms of depression or underactive thyroid glands. The brains of all individuals with Down syndrome show some abnormalities that are associated with dementias in the typical population but most older adults with Down syndrome do not have dementia.

Sensory impairments

People with Down syndrome are at risk for sensory impairments, which may affect developmental progress. Sensory impairments will affect the ability of children or adults to make sense of their world and to learn. If they are not recognised, treated and compensated for, then the individual's development will be slower than it could be.

Hearing loss

The incidence of mild to moderate hearing loss is significant among children with Down syndrome, with conductive losses of varying degrees affecting some 70-80% of children during pre-school years.

It is common for children with Down syndrome to have 25-40dB losses or greater due to middle ear dysfunction. This level of loss will certainly impair language learning in infancy and the early years for these children. Even a loss of 25-30dB will impair listening ability in the classroom or in a noisy environment. Some children will benefit from microsuction, grommets or hearing aids, but most will be helped by adapting their environment to reduce background noise and by the use of sign to support speech in the early years. It is important that all concerned with the care of a child are aware of any hearing loss so that they can compensate accordingly.

The risk of developing hearing loss continues into adult life so regular hearing checks are important throughout life.

Vision

Visual defects, particularly refractive errors (short and long sight), and squints are also common in children with Down syndrome, though usually adequately corrected with spectacles and/or surgery. Recent research indicates that visual acuity (seeing a sharp, clear image at different distances) may not develop normally in children with Down syndrome and observations of many parents suggest that depth perception (the ability to judge distances) may also be a difficulty for some children. A few children with Down syndrome are born with cataracts and some have nystagmus (a continuous rapid eye movement or wobble). However, most children seem to have vision that is adequate for reading and everyday tasks (corrected with spectacles, if necessary).

Additional developmental and educational needs

Research into developmental processes

Over the last 30 years, knowledge about the effects of Down syndrome on development has been steadily growing. During this same period, knowledge about the way in which all children grow and develop has advanced considerably. As the processes that influence cognitive, social and emotional development for all children are better understood, it is becoming easier to identify the specific reasons for the delays and difficulties experienced by children with Down syndrome in some areas of their development. This is leading to the design of more effective education and therapy programmes to help children with Down syndrome to make better progress.

All studies of the development of children with Down syndrome indicate that the children will progress more slowly than typically developing children and will have significant learning difficulties. However, not all areas of development are equally delayed, and much of the information that we have at present is based on descriptions of the progress of children with Down syndrome who have not benefited from effective interventions or inclusive schooling. This section lists the important additional needs as we understand them from research studies and many years of working with children with Down syndrome and their families.

Social development and communication

In the first year of life, babies with Down syndrome show only slight delay in their social and communicative development. They smile just a week or so later than average and then are very interested in other people, communicating with smiles, coos and then babble, just like all infants. They then move on to using gestures (pointing, waving) to attract attention and ask for what they want a little later but essentially like all children. Communicating in gesture is a strength but beginning to say words is a particular difficulty for most children with Down syndrome. Their understanding is usually ahead of what they can say and this is very frustrating for them, right through childhood. Teaching infants more signs (gestures) to use at this age helps to reduce frustration and enables them to continue to understand more words and to develop their spoken language.

Specific and uneven profile of learning difficulties

- Delayed motor skills
- Good social interactive and non-verbal communication skills
- Speech and language delayed relative to non-verbal ability
- Poor verbal short-term memory
- Good visual memory
- 'Visual learners' - literacy is often a strength
- Sensitive to emotional cues

See also:

- *The development of infants with Down syndrome (0-4 years) - An overview* [DSii-01-02]



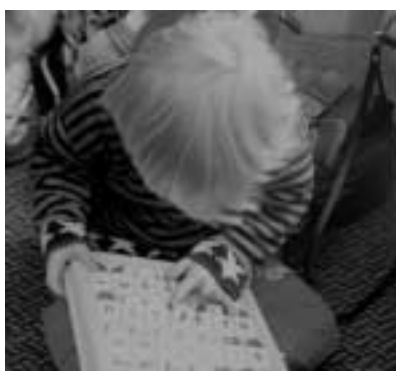
Additional development needs

- Physiotherapy to improve motor development
- Speech and language therapy to help to develop spoken language
- Early intervention to provide education programmes and introduce literacy
- Quality education in inclusive schools and colleges
- Social learning opportunities in clubs and in the community



See also:

- *Speech and language for individuals with Down syndrome - An overview [DSii-03-01]*

**Speech and language**

Speech sound work is also important, helping the child to listen to and repeat the range of sounds needed for speech in their native language, and it can start from the first year of life and will probably need to continue throughout childhood. Children without disabilities do not have complete control over speech sound production until they are 6 or 7 years old.

Most children with Down syndrome will benefit from specific speech and language teaching right through their school years. Recent studies even indicate that many adults with Down syndrome can considerably improve their speech and language skills with specific help. The necessary activities can be carried out by parents, carers or workmates.

Language games will help children with Down syndrome to learn the language faster than they would if left to pick it up by incidental learning (as other children do). Language is learned at home in the first years of life and parents will have the greatest influence on their child's progress because they are able to talk to them throughout their daily routines.

From as early as 2 years of age, reading activities can be used to teach language. Indeed, reading may be one of the most important aids to language and cognitive development for children with Down syndrome.

If available, the help of a speech and language therapist is invaluable to assist parents in choosing activities that will help their children. However, in many parts of the world parents will not have access to a therapist. The DSii modules on speech and language provide checklists of speech, vocabulary and sentence progress with enough detailed advice and activities to enable parents (or classroom assistants or teachers) to help their children effectively, even if they have no speech and language therapist available.

See also:

- *Memory development for individuals with Down syndrome [DSii-05-01]*

**Verbal short-term memory**

Verbal short-term memory skills seem to be less efficient and to develop more slowly in children with Down syndrome. In all children they influence language learning and speech processing abilities so activities that help to develop memory skills are important.

Motor skills

Most, but not all, babies with Down syndrome are floppy as their muscle tone is low at birth. The degree of hypotonia varies but most babies will benefit from physiotherapy during the first year of life, if it is available. Motor development, starting with the ability to reach, touch and explore objects, influences babies' opportunities to explore and learn about the world, and therefore their rate of cognitive or mental development. It is important to encourage babies to initiate movements, to want to kick, splash, reach, grasp, sit, move and walk. The target is to build up their abilities to initiate and control their own movement. If there is no physiotherapy available, parents can help their own child by encouraging all the natural opportunities to move and by using recently published illustrated handbooks.

See also:

- *Motor development for individuals with Down syndrome - An overview [DSii-12-01]*



Motor skills are also needed for increasing independence in self-help or practical skills, such as drinking from a cup, using a knife and fork and dressing, and later for drawing and writing, so progress in these areas will be influenced by gross and fine motor progress. Motor skills will continue to develop throughout childhood and into adult life.

Cognitive skills and knowledge

Normal experience

The main way in which children learn about their world is through immersion in the language and activities of home, school and community. Adults and other children talk to them, tell them new things and model activities and everyday behaviours.

Play

The other important medium through which they learn is play - play as we see it through childhood and then in leisure activities. Children with Down syndrome learn through play like everyone else, but they may benefit from more help. It may be important to demonstrate play activities and become a play partner in order to encourage play and exploration for the child with Down syndrome. Remember that they may not be understanding all the talk you use, but they are good at watching and learning by imitation.

Learning in school and college

Literacy and numeracy

There is a relatively small amount of research on the development of reading, writing and numeracy, but the information it provides indicates that children with Down syndrome can make steady progress in these skills through school and into adult life. They learn to read in the same way as other children, and can be taught in similar ways, though it is important to take account of their language delay. Reading skills are usually a strength for children with Down syndrome and often they are able to read better than might be predicted from their other skills. General knowledge is also extended by taking part in all aspects of the curriculum and project work in school.

Social learning and behaviour

Children whose development is delayed, and particularly when their language skills are delayed, are at risk of developing difficult behaviours. Many children with Down syndrome are no more 'difficult' than other children, and have socially acceptable and age appropriate behaviour. However, some children with Down syndrome display less appropriate behaviours and parents can find these difficult to control and stressful, as they disrupt family life. We know that age appropriate social behaviour will enable any child or adult to have a happier social life, accepted by friends and welcome in leisure activities. We also know that behaviour affects learning opportunities in school. If children cannot sit quietly, attend to instructions and take turns as part of a group, their learning opportunities will be reduced. It is therefore important that parents and all family members encourage age appropriate behaviour from infancy onwards, for all children with Down syndrome. It is so easy to 'spoil' them and not to expect age appropriate behaviour. This often happens without thinking as too many allowances are made with the excuse that they cannot be expected to conform as they are delayed.



See also:

- *Reading and writing for individuals with Down syndrome - An overview* [DSii-07-01]



See also:

- *Number skills for individuals with Down syndrome - An overview* [DSii-09-01]



See also:

- *Social development for individuals with Down syndrome - An overview* [DSii-14-01]



Behaviour is important

- Always encourage and expect age appropriate behaviour - right from infancy
- Predictable routines and clear rules help
- Behaviour may be a means of communication

Our experience leads us to encourage parents and teachers (and especially grandparents!) to expect and reward age appropriate behaviour at all times. This will be easier if regular routines are established from infancy for feeding and sleeping and other daily activities. Regular routines help the child to feel secure and to make life predictable. They also give the message that parents are in control and determine early behaviours, rather than always responding to the child's demands. However, remember that most behaviour is learned – good and bad behaviour – and can be changed by appropriate management. Behaviour change is not always easy and to be successful it needs to be planned. Everyone involved with the child needs to agree strategies and use them consistently. It is also important to recognise that changes in behaviour may take time.

The best way to become confident and competent socially, and to develop friendship skills, is to have as much social experience as possible with family, friends and in as many inclusive community settings as possible. This social experience offers opportunities to model age appropriate social behaviour and to increase language use.

As we stressed in the first section of this module, the social skills and empathy of individuals with Down syndrome are usually strengths, and parents and carers often comment on these positive qualities. However, they can also make children and adults with Down syndrome vulnerable, as they will pick up negative cues very quickly. If someone in the classroom or the club does not like them, then they will pick up negative messages from body language or tones of voice. Since they cannot usually explain how they feel, they may react by showing that they are unhappy and ill at ease in other ways – and promptly be blamed for negative behaviours.

In summary

Our priorities for meeting additional developmental needs are activities to promote motor development, most of which involve the practice of ordinary activities, awareness of good behaviour control from infancy, and a particular need to target speech and language development from infancy, with additional supports and strategies that are not simply part of ordinary development.



Implications for parents and professionals

The challenge for families and services is to meet the special additional needs of children and adults with Down syndrome within the ordinary world. Assisting people with Down syndrome to overcome their specific difficulties does require some targeted educational interventions, but not in isolation. Throughout this module we have emphasised that it is essential to recognise that most of their learning, progress and well-being is influenced by the same opportunities, education, social experiences and medical care as everyone else.

Families, education and healthcare professionals, and society as a whole, need to aim to offer people with Down syndrome normality first and foremost. Children with Down syndrome should receive the normal range of family stimulation, play, social experience and education opportunities as all other children. All people with Down syndrome should receive the same minimum standards of healthcare as all other people, supplemented with appropriate preventative management of their particular additional medical needs. The specific special activities targeted to help the child, such as signing or physiotherapy, should be provided in addition to normal childhood experiences. They should therefore be provided in regular settings, alongside typically developing peers.

In the following practical modules, we suggest many activities to assist the progress of children with Down syndrome. However, it is important that, as far as possible, these are absorbed into the usual daily activities at home and at school, and do not disrupt daily life for the child with Down syndrome, the rest of the family or classmates. There will be times when, in any family or class, it is appropriate to give extra time to one individual, but the overall balance needs to be considered. Being fully included as a much loved member of an ordinary, healthy and happy family is the most important experience for maximum growth and development. Therefore, it is important that the extra activities do not distort normal family life. So the challenge is to meet special needs without distorting family, community or school experience. The aim of support for the child or adult, at home, at school and in the community should be to facilitate their involvement and participation in the ongoing activities of everyone else in that setting.

Facilitating inclusion in everyday life, while optimising the development of the person with Down syndrome with effective interventions at the right time, is our ultimate goal.

"I think the most important message for parents to understand is that people with Down syndrome want to be independent, we want to lead as normal a life as possible. I know and so do most of my friends that we do need some support, but we also recognise that sometimes some of our family and friends do not understand that although we have an intellectual disability we are not babies. Everybody makes mistakes growing up. That's life. You learn from your mistakes and move on." (Gabriella Clark, Australia)



The challenge for families and service providers

To meet special needs within an ordinary environment:

- The child with Down syndrome will flourish as the much loved member of an ordinary family
- Children with Down syndrome will make the best progress when included in mainstream schools that make them feel valued and full members of the community
- People with Down syndrome will flourish when accepted in ordinary communities



References

- Clark, G. (2000) *How do I feel about having Down syndrome?* Available <http://www.hartingdale.com.au/~dsansw/gabriell.htm> [Accessed: 2000, September 17].
- Clark, G. (2000, December 13) RE: *Living with Down syndrome*. E-mail to Sue Buckley.
- Cromer, R. (1997) What is Down syndrome for me? *The 6th World Congress on Down Syndrome*. Madrid, Spain. (Transcript in DownsEd News, 1998, 1.5/1.6)
- Kingsley, J. (1999) Perspectives in Education. In Hassold, T. J. and Patterson, D. (Eds.). *Down Syndrome: A Promising Future, Together*. New York, NY, USA: Wiley Liss. (p. 280).
- Levitz, M. (1993) Community participation: Perspective. *Fifth International Down Syndrome Conference, Orlando, USA*. Transcript available: <http://www.down-syndrome.net/library/periodicals/pdst-news/03/7/001/> [Accessed: 2000, September 17].
- McFarland, D. (1993) Behavior: Perspective. *Fifth International Down Syndrome Conference, Orlando, USA*. Transcript available: <http://www.down-syndrome.net/library/periodicals/pdst-news/03/7/001/> [Accessed: 2000, September 17].
- Paez, M. (1993) Clinical care: Perspective. *Fifth International Down Syndrome Conference, Orlando, USA*. Transcript available: <http://www.down-syndrome.net/library/periodicals/pdst-news/03/7/001/> [Accessed: 2000, September 17].
- Taylor, J. (1993) Role of the family: Perspective. *Fifth International Down Syndrome Conference, Orlando, USA*. Transcript available: <http://www.down-syndrome.net/library/periodicals/pdst-news/03/7/001/> [Accessed: 2000, September 17].
- Trias, A. (1993) Education: Perspective. *Fifth International Down Syndrome Conference, Orlando, USA*. Transcript available: <http://www.down-syndrome.net/library/periodicals/pdst-news/03/7/001/> [Accessed: 2000, September 17].

Suggested further reading

- Selikowitz, M. (1997). *Down Syndrome: The Facts*. (2nd ed.). Oxford, UK; New York, NY, USA: Oxford University Press.
- Hassold, T. J. and Patterson, D. (Eds.) (1999). *Down Syndrome: A Promising Future, Together*. New York, NY, USA: Wiley Liss.
- Kingsley, J. and Levitz, M. (1994) *Count us in - Growing up with Down syndrome*. San Diego, CA, USA: Harcourt Brace.
- Van Dyke, D. C., Mattheis, P. J., Schoon Eberly, S., and Williams, J. (1995). *Medical and Surgical Care for Children with Down Syndrome: A Guide for Parents*. Bethesda, MD, USA: Woodbine House.
- Pueschel, S. M. and Sustrová, M. (Eds.) (1997). *Adolescents with Down Syndrome: Toward a More Fulfilling Life*. Baltimore, MA, USA: Paul H. Brookes Pub.
- Rondal, J. A., Perera, J., and Nadel, L. (Eds.) (1999). *Down's Syndrome: A Review of Current Knowledge*. London, England: Whurr.
- Nadel, L. E. and Rosenthal, D. E. (Eds.) (1995). *Down syndrome: Living and learning in the Community. Proceedings of the Fifth International Down Syndrome Conference*. New York, NY, USA: Wiley Liss.
- Stratford, B. and Gunn, P. (Eds.) (1996). *New Approaches to Down Syndrome*. London, UK; New York, USA: Cassell.

All of the books listed above are available from The Down Syndrome Educational Trust's mail order service.

Further information and advice

Down syndrome associations

Organisations exist in many countries to support people with Down syndrome and their families. Most have web sites (see below) with details of their activities and services.

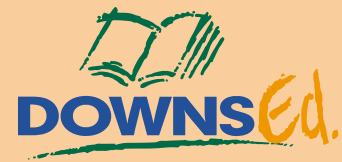
The Internet

A considerable amount of good, and not so good, information can readily be found on the Internet.

An exhaustive list is outside the scope of this publication. However, some of the more comprehensive (English language) sites are listed below. Most carry links to other sites of interest.

<i>Down Syndrome Health Issues</i> (this site also maintains a comprehensive list of links to web sites and discussion lists relevant to issues connected with Down syndrome)	http://www.ds-health.com/
<i>The Down Syndrome Information Network</i> (this site also offers a search engine that indexes other, recommended web sites)	http://www.down-syndrome.net/
<i>Down's Heart Group</i>	http://www.downs-heart.down-syndrome.net/
<i>Down Syndrome Research Foundation</i>	http://www.dsrf.org/
<i>Down Syndrome Quarterly</i>	http://www.denison.edu/dsq/
<i>Canadian Down Syndrome Society</i>	http://www.cdss.ca/
<i>National Down Syndrome Society (USA)</i>	http://www.ndss.org/
<i>Down Syndrome Association of New South Wales (Australia)</i>	http://www.hartingdale.com.au/~dsansw/

DOWN SYNDROME issues and information



Down Syndrome Issues and Information is a unique range of publications that provide comprehensive information and practical advice about the range of developmental, health and social issues related to Down syndrome in a concise and accessible format.

Written by expert researchers and practitioners, each section addresses a specific topic with a clear overview, practical guidelines and advice, and references for supporting material and additional resources.

Designed to meet the needs of parents, teachers, speech and language therapists, psychologists, and healthcare professionals, all advice and information is based on the latest scientific knowledge and wide, practical experience.

For the latest information on the series, see the *Down Syndrome Issues and Information* web site at <http://www.downsed.org/dsii/> or contact The Down Syndrome Educational Trust.

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Overview

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Memory

Reading and writing

Number skills

Motor development

Social development

Education

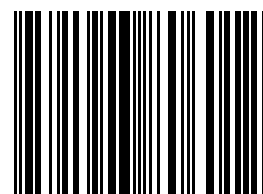
Family issues

Overview

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