An overview of the development of infants with Down syndrome (0-5 years)

Sue Buckley and Ben Sacks
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Summary – This module provides an overview of the development of babies and infants with Down syndrome from birth to five years. It describes the uneven profile of expected development, identifying strengths in social understanding, self-help skills and behaviour, and weaknesses in motor development and speech and language skills, the latter influenced by the high incidence of hearing loss, poor auditory processing and auditory memory skills. Visual processing and visual memory skills are a strength and can be used by parents and therapists to support children’s learning. By 5 years of age, many children with Down syndrome can achieve some of the same developmental targets as their peers, if this is expected of them. Most will be walking, toilet trained and able to feed themselves and dress with minimal help. Most will be able to fit into the expectations of the mainstream classroom, regulate their own behaviour and behave in a socially acceptable way. Most children will have significantly delayed spoken language. They will understand more than they can say, and their spoken language will not be clear. Many will have some of the basic concepts and knowledge for learning number, maths and reading. These achievements are possible, provided that parents have high expectations for social development and good behaviour from the first year of life, and that services offer targeted support for motor development and speech and language development. Like all children, progress for children with Down syndrome is influenced by family life and parents’ child rearing skills, inclusion with peers at home and in preschool, and the quality of education available. It is also influenced by biological make-up, and some children with Down syndrome are born with more biological disadvantages than others. The first priority for parents is to maintain normal family life. The most powerful influence on the progress of a baby with Down syndrome is to be loved, wanted and absorbed into the everyday life of the family and of the community. Specific teaching and therapies will definitely help, but must be kept in perspective and not allowed to create stress and anxiety for families.
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Terminology

The term ‘learning difficulty’ is used throughout 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.
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Introduction

The aim of this book is to provide an overview of development during the period from birth to five years and to assist the reader in integrating the material covered in the rest of the DSii books for this age group. These books each cover specific aspects of development, i.e. motor, social and behavioural, speech and language, working memory, early reading and numeracy, in detail.

This book is intended to help parents, families, teachers and other practitioners who work with under-fives. In the authors’ experience, they all wish to know what developmental progress to expect for a child with Down syndrome and how to help the child progress as fast as possible.

These two main questions are addressed, with milestones for development included, and a discussion of the wide range of individual differences in rates of development of children with Down syndrome. In order to answer the question of how to help children to progress, the reasons for their developmental profile are outlined as far as they are known, as this information should help to identify effective therapy and teaching strategies. The question of how to help also leads to a discussion of early intervention, what interventions are effective and the importance of balancing family needs with the needs of the baby with Down syndrome.

In the authors’ view, in order to understand the ways in which having Down syndrome affects children’s development it is necessary to consider what is known about the development of typically developing children. In the last thirty years, there have been considerable advances in our understanding of the processes of development, particularly in the areas of social learning, cognition and language. The greater our understanding of typical development, the easier it is to begin to understand the effects of a disabling condition such as Down syndrome on the processes of development. As we identify the specific effects of Down syndrome on development, we are in a better position to develop effective interventions and teaching strategies.
This is the approach taken throughout the DSii modules. We draw on research into the development of typically developing children, the specific research into the development of children with Down syndrome and research that has evaluated effective interventions, where it exists.

1. Development from birth to five years

What typically developing children achieve

During the period from birth to 5 years, children change from totally helpless infants to quite remarkably skilled individuals, able to socialise with others, co-operate and communicate in spoken language, to walk, run, climb stairs, feed, dress and go to the toilet independently. They are also beginning to write, to count and to read, and are able to sit and learn in more formal settings. Most children still need supervision for most of the day and some support for all these activities. However, the skills and knowledge that children acquire and the developmental progress that they achieve between birth and five years are very significant (see Figure 1).

This developmental progress is all the more remarkable when we consider the fact that most of this progress is not the result of specific planned teaching. Most children learn to walk, talk, take care of their daily needs and socialise with others by being absorbed into the everyday social worlds of their families. They are encouraged to progress by those around them but, with the possible exception of toilet training, reading and counting, they are not taught. Parenting is a process of modelling appropriate actions and language, encouraging children to master new words, to dress, to kick a ball, and rewarding progress in independence and socially acceptable behaviour. Parenting is more about being sensitive, responsive and rewarding than about explicit teaching in the first five years of life. It is about providing a wide range of learning and social learning opportunities, through toys, books, the media, social activities and outings to the park, shops, farm and beach.

One of the major breakthroughs, which led to significant progress in the care and education of children and adults with developmental disabilities and learning difficulties in the 1960s, was the recognition that they are not always able to acquire the skills usually acquired by five years without explicit teaching. In other words, skills and progress in development, which seem to be acquired by most children if they are simply absorbed in an adequate social world, may need to be taught, in small steps, to children with learning difficulties.

Influences on development

Development is not fixed by genes at birth

Development is a process, a dynamic, transactional and social process. Most babies are born with the potential to make typical developmental progress in all areas of their development, but to do so they have to be able to interact with the world, to move, explore, and to have people around them who talk to them and react to their behaviours. At each step, the baby has to be able to store the information that he or she is gaining from the world and to be able to practise the new skills. Later steps in development are built on earlier ones. A baby who is placed in a barren orphanage with no toys and little human contact will not sit up, smile or talk at the usual ages. At any age, therefore, the development of a particular child, including those with Down
An overview of the development of infants with Down syndrome, is the result of an interaction between that child’s biology and innate learning potential and the social and learning opportunities that he or she has experienced. It is not fixed in any simple way by genes at birth.

**Development is a dynamic, social-interactive process**

While much development from birth to five years is not explicitly taught, there is much evidence that it is influenced by the sensitivity and responsiveness of parents and carers, and by the quality and range of the learning opportunities available to children. While parents and carers may not be aware that they are teaching children as they talk to them, play with them and read to them, parents and carers are often engaged in explaining the world to their children as they talk or read to them and scaffolding their learning as they play. **Scaffolding** means supporting a child to succeed at a task that he or she cannot yet complete on their own. This is often done when helping children to find out what a new toy can do, helping them to complete a jigsaw or to count for example. The adult does not take over, they join in with the child, just supporting and demonstrating as necessary when the child is not sure what to do next, so that the child is able to see how to succeed. Therefore, development is **socially mediated** – that is, children learn in social interactions with more competent others in their world, such as parents, brothers and sisters, grandparents, friends and teachers.

**Curiosity, motivation and self-esteem**

Children’s learning is also influenced by their curiosity and motivation. Children are usually active explorers of their world from the first months of life and in their play, they seek to find out what toys can do.

As they develop spoken language, children learn by asking as well as investigating. Children’s learning is influenced by their self-confidence and self-esteem. Children who are confident explore and learn faster than those who lack confidence. Confidence may be influenced by success but it is also influenced by children’s sense of self-esteem (self-worth), which comes from being secure, loved and valued.
Brain and behaviour

Further, while brain development and brain function underpins all that children do, brain development is also a dynamic and ongoing process after birth and it is influenced by input and activity. As children learn and develop, so the brain stores that information, and brain structure and function change as new learning takes place. This means that intervention should take account of normal developmental milestones and try to ensure that a child who cannot engage in some of the age-appropriate activities independently is being assisted to experience them and helped towards achieving them with support and practice. This will ensure that they are at least gaining some of the brain stimulation that would be typical for their age. It is also necessary to be very cautious when interpreting studies of brain structure and function in children and adults with Down syndrome. Any apparent abnormalities described could be the result of the extra chromosome material and the way that it has affected the brain’s development but they could also be the result of delayed and different progress in learning and mastering new skills.

Summary

For all children, including those with Down syndrome, their developmental progress at any age is influenced by their biological make-up and their opportunities to learn and develop throughout their lives. In infancy, much learning is influenced by the social relationships experienced in families and then by social learning with other children and adults outside the family. It is also influenced by children’s self-confidence and self-esteem. Brain development is a process which continues through life and brain function and structure are influenced by learning and progress.

The development of children with Down syndrome

Children with Down syndrome make progress in all areas of development, in the same way as other children but usually at a slower pace. Some areas of their development are usually more delayed than others, leading many researchers to now describe a specific profile of strengths and weaknesses. However, before describing this profile in more detail, it is important to stress that any group of 100 infants or preschool children with Down syndrome will vary as widely in abilities, behaviour, personality characteristics, size and appearance as any group of 100 ‘typically developing’ preschoolers. Their development is influenced by their biology and by their social and learning opportunities, like all other children.

The effect of the extra chromosome on the foetal development of babies with Down syndrome is not the same for all the infants. For example, nearly half are born with congenital heart defects but the other half have no heart abnormalities, and while some children have bowel abnormalities, most do not. It is clear that the effects on physical development vary, for reasons not yet fully understood, and it can be predicted that the effects on brain development and learning abilities also vary between children. Some of the individual differences in rates of progress are therefore due to biological differences at birth. Some children with Down syndrome will have a greater degree of disability than others, however good their family care and stimulation, their therapy and school services. It is important to stress this point,
as many parents wrongly blame themselves when their child makes slow progress.

The progress of most children with Down syndrome is also influenced by the stimulation and love provided in the family, the opportunity to be included in all aspects of community life and by better quality education. As a group, children with Down syndrome are progressing faster and achieving more than they did 25 years ago. [3]

**Children with Down syndrome are individuals**

Children with Down syndrome are all individuals. The conventional stereotypes are inaccurate and unhelpful. In physical appearance, they look like their parents and brothers and sisters, just like all other children. They do have some physical characteristics as a result of having Down syndrome but they do not all look alike and neither do the ‘Down syndrome’ features dominate their appearance. Similarly, children with Down syndrome vary widely in personality, from being extroverted, friendly and sociable to being introverted and shy. Some children are always calm, others are anxious. Some children are flexible and adaptable, others find change difficult and may have a tendency to be obsessional in their behaviours. Some children are easy to manage, are happy to be co-operative and to conform at home and in school, while other children are difficult to manage and like to have their own way, or to be in control, at home and at school.

Similarly, in all areas of development, children with Down syndrome vary in their progress. Some children will be fairly slow to achieve the motor milestones of reaching, sitting and walking and others will show little motor delay, and some children with Down syndrome will have more difficulty learning to talk than others.

The reasons for these differences will be partly influenced by genetic makeup and partly influenced by the way in which parents, carers and teachers have been able to help the child to adapt to the demands of growing up. If a child with Down syndrome is more severely delayed than is typical, it is particularly important that his or her parents have extra help and support from services and from parent support groups.

Each baby and child with Down syndrome is an individual and he or she has the same needs as any other child plus some specific needs, and it is important that everyone concerned with a child with Down syndrome remembers this. It is helpful to know about the specific needs that are usually associated with Down syndrome and these are described in the next section, but having Down syndrome does not define any individual child.

**Additional difficulties**

It is also important to remember that a child with Down syndrome may have additional difficulties, like any other child. A small number of children with Down syndrome have additional medical complications, like seizures or other illnesses, which may affect their development. Similarly, a small number of children have autistic spectrum difficulties, attention deficit or hyperactivity. These additional difficulties affect less than 10% of children with Down syndrome but they should be recognised and treated in their own right when they do occur. These difficulties are discussed in a little more detail on pages 9-10.
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Healthcare needs

Children with Down syndrome are at greater risk for some illnesses and for hearing and visual difficulties. Any child’s developmental progress will be influenced by illness or sensory difficulties, so that it is important that all healthcare issues are understood and addressed. The second section of this module (see page 21) provides a guide to the healthcare needs of children with Down syndrome, explains assessments and treatments and gives references to further reading. It is perhaps worth noting that some illnesses will present with obvious symptoms but some may not, for example, ear ache or tummy ache. A small child may have no way of expressing that he or she feels ill or is in pain except by being unhappy and, maybe, irritable, unco-operative or difficult. Therefore it is always important to consider and rule out illness reasons if a child’s mood changes, they stop making progress or they are difficult, before assuming they are simply being unco-operative or naughty.

Achievements at 5 years of age

Most children with Down syndrome can achieve a number of the same developmental goals at 5 years of age as other children. Most five-year-olds are walking, toilet trained, able to feed themselves and put on at least some of their own clothes.

Most 5-year-olds are able to be part of an age-appropriate group and can conform to the social expectations in the classroom. They are able to sit at a table, listen to the story and follow the teacher’s instruction - with some needing no help to do this and others needing some support. Most children can control their own behaviour and are not anti-social. They have appropriate understanding of the emotions of others, for example, when they are happy, sad or hurt.

Therefore motor skills, social progress and behaviour are strengths. However, most 5-year-olds with Down syndrome will have significant delays in spoken language - typically talking in 2 or 3-word phrases, and the words may be difficult to understand. Some children will have a knowledge of the maths concepts needed in the classroom, and be starting to count, despite general language delay. Some children will be reading a sight word vocabulary and know their letter names and sounds, despite having general language delay.

A specific developmental profile

Over the last 15 to 20 years, researchers have made progress in understanding the effects of having Down syndrome on development, though there is still much more to learn in order to fully understand how to help the children. Research has identified a specific profile of developmental strengths and weaknesses. However, while this profile is typically associated with Down syndrome, the degree to which any individual with Down syndrome shows this pattern will vary. It is helpful as a guide to understanding any child’s developmental needs and learning profile, but it should be treated as a checklist for any individual child, as he or she may have all or none of these characteristics and if he or she does have some, the degree to which they show any strength or weakness will need to be assessed in order to develop an appropriate therapy, early intervention or teaching programme.

While children with Down syndrome experience some delays in all areas of development, the extent of the delay is not the same across all areas of development.
Social understanding and social interactive skills are a relative strength and less delayed than speech and language skills. Most children with Down syndrome make eye-contact, smile and interact by cooing and babbling from the first months of life, and show little delay in social interactive skills. They are socially sensitive and understand the non-verbal cues to emotions, such as facial expression, tones of voice and body postures, from the first year of life.

Motor skills, including reaching, sitting and walking, are delayed but the main milestones are steadily achieved and most children become mobile and independent in self-help skills, such as feeding and dressing, which require motor skills.

Speech and language skills are more delayed than the children’s non-verbal understanding and reasoning abilities. This is a pattern of specific language impairment. Most children with Down syndrome understand more language than they can use as a result of specific speech production difficulties. For this reason, learning to sign will help the majority of children to communicate, to show their understanding and reduce their frustration. Hearing difficulties, usually due to ‘glue ear’ are common (see p.23) and contribute to speech and language difficulties.

For most children with Down syndrome, the most serious delay that they experience is in learning to talk. This is not only frustrating but it has serious consequences for all other aspects of their social and cognitive development.

As children learn to talk, each new word that they learn is a new concept or piece of information about their world. Once they can string words together, speech becomes a powerful tool for learning and for communicating with everyone in their world, and it also becomes a tool for thinking, remembering and reasoning. We carry out these mental activities using silent speech in our minds. While we can also use visual imagery to imagine and recall events, reasoning with the use of language is considerably more powerful. It follows that a serious delay in learning to understand and to use language will lead to delay in all aspects of mental or cognitive development. Conversely, if we can improve the rate at which children learn language, this should benefit all areas of their social and cognitive development.

Working memory development, particularly verbal short-term memory, seems to be specifically impaired – again not progressing as fast as would be expected for non-verbal abilities – and this has consequences for the children’s ability to process information.

Visual memory and visual processing are relative strengths, while auditory processing and auditory memory are more impaired. This means that children with Down syndrome should be thought of as visual learners and all teaching supported with visual materials.

Reading ability is often a strength from as early as two years of age, perhaps because it builds on visual memory skills, and reading activities can be used to teach spoken language from this time.

Number seems to be relatively more difficult for children with Down syndrome and their number skills delayed relative to reading skills.

Social behaviour is a strength as children with Down syndrome are less likely to develop difficult behaviours than other children with similar levels of cognitive delay. However, children with Down syndrome are, as a group,
more likely to develop difficult behaviours than non-disabled children of their age.

Most children with Down syndrome are socially sensitive and understand the non-verbal cues to emotions, such as facial expression, tones of voice and body postures, from the first year of life. They can behave appropriately in showing concern, or becoming upset. However, this sensitivity can also make the children vulnerable as they will quickly pick up on negative emotions such as anger, dislike or rejection. As they are usually not able to explain how they feel, their distress will be expressed in behaviour. Some children with Down syndrome can be quite naughty and difficult to manage at times, at home or at school, and they may use their understanding of people’s behaviour to be unco-operative and the centre of attention. It is always possible to change behaviour and to encourage and teach age appropriate behaviour. However, it is not easy to change difficult behaviours that have become habits, and most difficult behaviours can be avoided with calm routines and good control from infancy.

In order to provide detailed overviews of the research relevant to the development of children with Down syndrome in this modular series, individual modules address social development and behaviour, and motor development, and then four cognitive areas - 1) speech, language and communication, 2) reading and writing, 3) number and 4) working memory skills. This division is somewhat arbitrary and reflects the focus of the team of authors. Content that might be covered in a cognitive module (for example in a Portage programme) is shared between the four cognitive modules. Self-help skills are covered in social development and behaviour.

This leaves some topics to be addressed later in this module that are relevant to all aspects of children’s development, such as attention and concentration, motivation and persistence, play, curiosity and exploration.

Milestones, individual differences

Parents of typically developing children have some idea about expected rates of development, which they can use to decide whether their children are making appropriate progress or whether they should be worrying about their progress. For parents with children with Down syndrome, guidelines are equally important but more difficult to find and to interpret. In the authors’ experience, parents do wish to know at what age their child might sit, walk, say his or her first word or become toilet trained. It is helpful to know what to expect and to have some idea if there should be concern and additional help or assessments sought.

The tables on pages 32-37 have been compiled from all the available sources that the authors could identify. The reader should, however, note two important points which make these milestone guides less reliable than those available for typically developing children - the sample sizes and the range of individual differences. The studies of babies and infants with Down syndrome have usually been of small samples of less than 30 children, while milestone data for typically developing children is based on many hundreds of children. These limitations need to be considered when using the milestones for guidance. All milestone charts give the average age at which a child can be expected to reach a milestone plus the range around that figure that identifies the range of ‘normal’ variation. For children with Down syndrome, this range is larger than it is for non-disabled children, in other

See also:
- Strategies for changing behaviour and developing social skills for individuals with Down syndrome

Using Milestone Tables
- Milestones give a guide to expected achievement and the order in which skills are achieved.
- Some children progress faster in some areas of development than in others. Progress in one area does not necessarily predict progress in another area.
- Children can vary in their rates of progress from year to year.
- Development and progress in school years cannot be predicted from progress in pre-school years. Some ‘slower starters’ make faster progress later.
words there is greater variation in rates of progress between children with Down syndrome.

In the tables, milestones are given for behaviours that represent an observable step forward, selected from the sources available. In each of the detailed modules, milestone data is also included, for example, for speech and language, counting or reading progress, in more detail.

**Predicting development**

While the authors believe that milestones are helpful, they would stress that it is not possible to predict children’s future development in their early years. Some babies show faster development of motor skills than others, but this cannot be assumed to indicate that these babies will also show faster progress with speech and language development, for example. The authors also have experience of a number of children whose progress seemed very delayed in the first 12 to 18 months of life, but who made rapid progress from then on. In other words, the authors, with experience of many hundreds of babies with Down syndrome between them, would wish to stress that it is not possible to predict the later progress of children with Down syndrome from their development in the first 3 to 4 years of life.

**Wide range of development**

It is clear from the milestone data that children with Down syndrome vary widely in their rates of progress. Some children make much slower progress than others and it is not possible to explain these differences fully at the present time or to predict them. Typically developing children also show a wide range of rates of progress, due to both different genetic make-ups and to social and educational learning opportunities and the range for some 85-90% of children with Down syndrome is probably due to exactly the same factors. The development of approximately 10% to 15% of children with Down syndrome is being affected by additional difficulties. This group of children show the greatest developmental delays and may be significantly more disabled as adults than the majority of individuals with Down syndrome. Children in this group are likely to have additional medical or neurological problems.

**Children with more severe developmental delays**

The most common reasons for the more severe levels of developmental delay seem to be health issues, autism and attention deficit/hyperactivity disorder.

**Health problems**

In a study by the authors of 90 teenagers with Down syndrome, it was clear that one reason for more severe developmental delay was additional health difficulties such as seizures and neurological damage. However, for some children with severe developmental delay, the reasons cannot be identified. The prevalence of medical and psychiatric disorders in people with Down syndrome varies from those which have a lower incidence to those which are relatively common and some of these are described in the Health section of this module (see p.21).
Autism

It was once thought that Autistic Spectrum Disorders (ASD) were not found in individuals with Down syndrome. This is now known to be incorrect, but the incidence of ASD in people with Down syndrome remains a matter of some debate. It has been estimated to affect some 3-7% of children and adults. The reason for this uncertainty is that there have been no large scale controlled studies of this issue and, more importantly, that the diagnosis of ASD is too uncertain to produce reliable data.

The diagnosis of ASD is based on obtaining the developmental history of the individual and information about their behavioural patterns. At present there are no objective findings in ASD which are of diagnostic value. ASD is a spectrum disorder which covers a very wide range and there are many behavioural features which are associated with this group of conditions. However, many of these symptoms are non-specific in that they may be found in a large number of other disorders.

Some of the main characteristics of the condition are:-

• A lack of behaviours in which points of interest are shared with others.
• Inappropriate social behaviour which is not understood by other people.
• Abnormal interpersonal relationships, expressed as the inability to develop intimate, reciprocal communication with other people.
• Language usage which is not only delayed but abnormal in kind.
• Rigid, unimaginative style of thinking and behaviour.
• Play patterns which are repetitive, show a lack of the symbolic meaning of toys and inability to pretend.
• Obsessional/repetitive behaviours and preoccupations.

A child displaying one of these characteristics, or even two or three, does not necessarily have autism. For a diagnosis of autism to be appropriate, a majority of these symptoms need to be present.

Attention Deficit Hyperactivity Disorder (ADHD)

This condition is sometimes confused with ASD, especially if the child has severe learning disabilities.

The level of intrinsic activity and liveliness in children varies enormously and the vast majority of children with Down syndrome are normal boisterous youngsters. However, a small number are so overactive that their entire pattern of behaviour is disorganised. They are characterised by their short attention span, impulsiveness, ‘silly’ social behaviour, clumsiness and constant movement which is little affected by environmental influences. The response of children with ADHD to the commonly used medications is interesting because they become calmer and more capable on drugs which are stimulants.

The management of this condition consists of a combination of behaviour modification and drugs. If parents and/or carers observe behaviours in a child with Down syndrome which are similar to those described above it is important to obtain a diagnostic assessment from a specialist paediatrician or a child psychologist with experience of children with learning difficulties to find out if the child has additional problems.
Meeting the needs of children with Down syndrome

The profile of development discussed in the last section suggests or identifies some priorities for assisting the development of children with Down syndrome.

The first months of life - health and family priorities

Health

All developmental progress will be affected by illness or ongoing health problems. Ideally, all babies with Down syndrome should be in the care of a paediatrician, who will screen for heart defects and be alert for any health risks associated with Down syndrome. Parents should also have access to support from health workers, such as health visitors, for general advice. Sometimes help in establishing feeding is necessary, though many babies feed and breastfeed well. The common health issues for parents and carers of children to be aware of are dealt with in the Health section on page 21. It is particularly important to be alert to hearing difficulties as they affect some 80% of preschoolers and even mild conductive losses can have a significant effect on the children’s development. A detailed DSII series of Health modules to inform doctors and healthcare professionals as well as parents, will be available during 2002.

The family

A further priority in the first months is for the family to adjust to the birth of the baby with special needs. This will be helped by the availability of accurate information on Down syndrome and the sources of local support such as parent groups and Down Syndrome Associations. In some countries, financial benefits may be available and parents need to know what these are and how to apply for them.

Social development in infancy

In the first year of life, social development (smiling, cooing, babbling and socialising) is usually only slightly delayed and in the first months of life babies with Down syndrome are usually much like other babies in their social behaviours and early communication skills. They are responsive and enjoy social interactions with their parents and carers.

Motor development

Motor development is the next concern as babies’ first motor skills, the ability to reach, grasp and hold, are important for beginning to explore their physical world and sitting, rolling, crawling and walking enable babies’ to explore on their own. Delays in fine and gross motor skills therefore influence cognitive and language development, as they reduce the opportunity to explore and to move around to socialise. Assessment by a paediatric physiotherapist should be available to all babies with Down syndrome. Some babies will be fine with normal stimulation and exercise but others will benefit from expert advice, equipment and exercises.

The authors encourage all parents to find activities for children in the community for sports such as swimming, gymnastics, horse-riding, dancing or football. These sporting activities contribute to health and motor skill development - and a sporting skill developed in childhood provides teenagers and adults with leisure activities and social opportunities.
Learning to talk

The next developmental target is learning to talk, which typically developing babies begin to do from 12 months on. All babies with Down syndrome will benefit from the support of a speech and language therapist from birth, as although words come in the second year of life, the foundations are being laid in non-verbal communication skills and babble from the first weeks of life. Babies are beginning to understand the words used around them, and to point to objects from about 9 months of age. Babies with Down syndrome may have hearing difficulties, and the use of signing so that “they can see what you mean” has been shown to be helpful. Parents can use signs to help their baby to understand from 9 months of age.

Babble is practice for speech sounds and this is also developing from the first year of life. In the second year of life, babies begin to use single words and then join words together. Babies with Down syndrome can often sign words before they can say them, as speech production difficulties hold back spoken words.

Speech and language therapy, targeting understanding and production of words and sentences, and targeting clear speech production (articulation and phonology) is therefore important throughout the preschool years. However, learning to talk is a daily activity and is mostly learned with parents, who can help their own children if they have no access to therapy. The speech and language modules and checklists are designed to be used by parents, ideally with the support of a therapist, but on their own if necessary.

Behaviour

By twelve months of age or earlier, the issue of encouraging socially appropriate behaviour needs to be considered. Many typically developing babies are already controlling their parents at this age – for example demanding to be picked up, arranging their own sleeping schedules, showing preferences for foods and eating behaviours – and by two years of age demands for independence and tantrums in order to determine what they will and will not do are common. Children with learning difficulties, and in particular children with delayed speech and language skills, are vulnerable to developing difficult behaviours. Children with Down syndrome often display more difficult behaviours than typically developing children, but less difficult behaviours than other children with similar levels of learning difficulty – perhaps reflecting their ability to understand non-verbal social and emotional cues. However, the authors firmly believe that ‘prevention is better than cure’ and much difficult behaviour can be avoided if parents have thought about the issues and adopted good management strategies from the first year of life.

Professionals involved with providing services and support to families at this time should be competent to advise on good behaviour management techniques. Two simple pieces of advice will help to avoid problems and that is – establish settled routines so that the baby can feel secure and anticipate his or her daily activities and – be in control. Routines and set times for mealtimes and bedtimes also mean that parents are in control – they, and not the baby, determine the baby’s behaviours. Babies and children feel more secure in an environment of order, warmth and control. Because behaviour and more advanced social skills are so important for the future
Cognitive development is a term used by psychologists and teachers to cover all the skills involved in learning and mental processing, i.e. thinking, reasoning, remembering and learning skills. In typical development, speech and language skills play a central role, as thinking, reasoning and remembering are usually carried out by means of ‘inner speech’. Young children predominantly ‘think out loud’ i.e. talk to themselves, especially when into imaginative play and it takes several years to prefer to think silently. Many adults still engage in thinking out loud at times.

Cognitive development also refers more broadly to acquiring knowledge about the world and understanding the physical and social world. Knowledge is obtained through all our senses, with vision and touch being the most important in the first year of life. Babies are watching all the activities around them and exploring toys and objects within their reach. The way in which a baby or young child plays with toys is usually a good indication of the level of understanding that they have reached about the toy and how to use it (posting boxes and stacking toys, for example).

In the second year of life, children begin to show how they are understanding the behaviours and actions of those around them, and the events in their world, as they play in imaginative ways with their toys (making meals, putting dolly to bed, playing at being the farmer and playing with trains). The role of play in children’s development is therefore a very important one and play activities can be used to teach many things. Structured teaching is also important by the second year of life. By structured teaching, we mean planned teaching activities to teach vocabulary (matching and selecting pictures) or to learn colours and counting, by sitting together on the floor or at a table, copying the actions of a ‘teacher’ and following instructions.

Children are also learning during all their everyday activities at home, when out shopping or at the park, and in playschool. During daily activities, play and structured teaching sessions, adults can scaffold children’s learning, that is they can help children to reach the next step in their play and in understanding the task, by modelling - showing them what to do and by explaining - talking about what to do. They can also show pleasure and make games and teaching activities fun and rewarding by being interested and joining in children’s activities. The way in which these different approaches to teaching children can be used is discussed further in the section on Early Intervention later in the module on page 16.

Cognitive development in the first 1 to 2 years focuses on children’s ability to develop increasing abilities in manipulative play with toys and then their understanding of the world around them demonstrated in their imitative and imaginative play. As their understanding of language grows, they learn more about the characteristics of the objects and events in their world, the size, colour and shape of things, whether they are hot, cold, wet, or dirty. They learn about actions, running, swimming, washing, moving fast or slowly, and they learn about place, putting something in, on, under, behind another object. This is all cognitive knowledge and it is usually taught with the words for the concepts. Learning about attributes such as size, shape and quantity and time is laying the foundations for the maths curriculum in school.
Speech and language development is inextricably linked to cognitive development in typically developing children and, when children have speech and language delay, it is important to recognise the impact of this and still try to teach as many concepts as possible with toys and real objects, as many of the attributes are visually or perceptually obvious and can be experienced by looking and touching. Children with Down syndrome will be helped to learn by shared play activities and all opportunities that are available during daily activities. They will also benefit from structured activities and this is why, in many countries, early intervention services are available and families have the support of a home-visiting teacher.

By the preschool years, 3 to 5 years, children are learning to count and they are gaining wide experience of books, ready to learn to read. They are also learning to gain pencil control for writing, by colouring and drawing. Children with Down syndrome can begin to learn all the same things, if at a slower pace. The author’s encourage games and activities to teach concepts, number, reading and writing skills throughout the preschool period and cognitive development is divided between the Speech and Language, Number, Reading and Motor skills modules. In addition, we have a module on memory, as memory skills, particularly working memory skills are important for all daily activities and for learning. During the early years to 3 years, most learning will take place at home but from 3 years, many children have the opportunity to join a play group or kindergarten and learn with other children.

Attention and memory

In order to learn, children have to attend to information in their world, usually by looking or listening or touching, and they have to attend long enough to take in the information and to remember it. Therefore attention and memory skills are important.

Attention

Most babies and children with Down syndrome do not have any attention difficulties, but some children do seem to have limited attention from infancy. It is therefore important to engage children in activities which require them to attend, using play activities and picture book reading to engage children’s attention, for example, from the first year of life. Some children seem to have difficulty focusing their own attention and so are not able to play or occupy themselves without support. They may then become quite difficult to manage if they are physically mobile. Other children may be difficult to engage in one-to-one tasks at a table and this will lead to difficulties in preschool and school. It is, therefore, important to encourage babies to engage in early ‘face-to-face’ babble games and to continue from this to playing with toys and looking at books together by 12 months or so. If a child’s ability to attend is limited, it is helpful to find activities that they enjoy - often noisy toys or toys with moving parts are motivating - and then take turns with them to keep them engaged for longer periods. Only extend the period that the child is expected to attend for in small steps. Looking at books together is often a good way to move towards sitting still for more formal learning at a table. To encourage children to sit at the table, choose activities that are fun, that the child enjoys, and can be successful at. Often it helps if the table activity can be a group activity with more children or adults, to take the ‘pressure’ off the child with Down syndrome.

Attention and motivation are usually, though not always, linked. Sometimes children are described as having attention difficulties but, in fact, they will
attend and concentrate for long periods when the activity is one they enjoy. However, some children do have attention difficulties and it is important to be alert to this possibility and encourage the development of their attention skills in the ways suggested.

Memory

The development of memory and memory skills is a large research area, with new ideas appearing all the time. It is clear that there are a number of memory systems for remembering different sorts of information but for the present discussion, memory can be divided into long-term and short-term memory. Long-term memory refers to all the information and learned skills that are in long-term store - the usual use of the term memory. Short-term memory refers to the systems that hold information for brief periods, perhaps while carrying out a task like adding up prices in the shop or remembering a telephone number while dialling. This information may or may not move on into long-term memory stores. This short-term memory system is aptly described as working memory by some researchers, as it supports conscious mental processing. Research into the memory skills of children with Down syndrome has focused largely on short-term or working memory. Their long term memories seem to be good, and information and skills are retained once learned. However, their working memory systems do not develop at the expected rate and they have particular difficulty with short term storage of verbal information. This makes learning to talk and processing speech in everyday situations particularly difficult for most children with Down syndrome. However, their ability to process visual and spatial information in short-term memory is better, so that it is important to use pictures and visual information to supplement spoken information, in order to help children with Down syndrome to learn.

The development of working memory skills is explained in full in the module on memory. Working memory capacity increases during childhood and it is probable that children's memory skills can be improved in a number of ways, so memory games become important from 2 years of age in children's play and in early intervention and preschool programmes.

Social development and independence

During the second and third years of life, children develop their social skills as they learn to mix with a wider range of adults and children and to communicate and play with them. It is beneficial for children with Down syndrome have the opportunity to mix in this way and to learn to be able to be part of the group at preschool. This is important preparation for school, and play with other children will help them to learn both socially and cognitively. Most children with Down syndrome are disadvantaged by delayed spoken language which makes communicating with others and joining in play more difficult for them. However, they learn a great deal by watching and imitating - probably because they are not able to learn easily from all the speech going on around them. The spoken language of children with Down syndrome will also benefit from being able to be in a mainstream preschool environment as they will have competent partners and role models in a mainstream setting.

Children's behaviour changes during the toddler period as they learn to control their behaviour and impulses. Often children go through a period of tantrums as they want to be independent and not conform, but by 3 to
4 years, most children have matured through this phase and are learning to self-regulate their behaviour and to follow instructions and requests. They learn more about how to behave as part of a group, to share, to take turns and to follow the instructions of the teachers in preschool, ready for primary school. It is very important that children with Down syndrome learn to behave in a chronologically age-appropriate manner if they are to be able to join in mainstream activities at school and in the community.

Self-help skills and independence
During the preschool years, children become largely independent, able to feed themselves at mealtimes, able to dress and undress with help with fastenings and able to go to the toilet without assistance. It is important that children with Down syndrome achieve these skills before 5 years if possible, so that they can cope in school. The speed with which children become independent in these areas is influenced by the expectations of their parents.

Early intervention and approaches to teaching
In many communities, families are offered an early intervention service which may start in the first year of life and is provided in the family home. Early intervention services started in the 1970s, with the aim of providing activities to promote the development of children with developmental delays and difficulties. It quickly became clear that the home-teacher provided more than just teaching activities and a knowledge of the child’s disabilities. He or she, as a regular visitor to the home (often weekly), soon became a family friend who valued the child, provided emotional support for the family and information on rights and services.

In the authors’ view, this type of early intervention support should be available to families. Ideally, home visiting teachers should have appropriate training and experience, but where resources are scarce, volunteers and other parents can provide effective services. Parents have consistently reported that this type of service is valued, though the research literature is not conclusive in demonstrating the benefits for accelerating the progress of children with Down syndrome. This may be because many of the early projects that were set up did not adapt their teaching approaches and curriculum to take account of the profile of strengths and weaknesses described for the children.

However, the authors would also stress two cautions:

1) Early intervention activities should not require more than twenty minutes a day of parents’ time, if they are structured activities. Ideally, the information and advice provided should help parents to absorb effective ways of supporting their child’s development into ordinary daily activities.

2) Early intervention activities should not disrupt family life, invade the family’s privacy or cause distress. The provision of home teaching implies that the child’s progress will be better if parents follow the activities. This is a common recipe for creating anxiety and guilt, and parents may feel that slow progress is their fault because they did not work hard enough with their child.

The most important influence on the child’s progress is to be a much loved child in a happy family - involved in all family activities. This needs to stressed to all families, and professionals need to help families to keep this perspec-
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It is the daily experience within the family, school and community that will shape the confidence, personality, social and cognitive progress for a child with Down syndrome. The structured teaching and planned activities may help - but only as an ‘extra’ to daily quality experiences.

It is easy for families to undervalue their daily life experiences and parenting contributions to their child’s development and overvalue the special activities. Family life should come first and not be upset by too many extras for the child with Down syndrome. However, most parents do want to be sure that they are helping their child to progress, and the appropriate support of a home teacher can be invaluable.

There are a variety of ways in which adults can help children to learn, starting with play, planned games and then structured teaching.

**Play**

All children learn through play and we play with babies from the first months of life. Sometimes children with learning difficulties need some help to learn to find out what toys do and how to play with them, therefore it is important to play with babies and infants with Down syndrome. It will be helpful to show the baby what a toy does, how to get it to make a noise or move, how to screw or unscrew a toy, how to hide and find a toy - under a blanket or in a box. Taking turns with the baby is often a good way to show them how to do something, or having two toys, so that both partners can shake the rattle, for example. In our experience, it is often necessary to show children how to get into imaginative play by joining in. For example, have 2 dollies, cups, flannels etc and give dolly a drink or wash dolly’s face, together. Imaginative games in the second year of life are a very valuable opportunity for teaching new language - helping the child to link two or three words together as you say “Can you wash dolly’s face”, “Watch me put dolly in the bath”. Play is, then, the first and perhaps the most important way to help children to learn and as they get older, games will be the extension of play as the fun way to teach. However, structured teaching is also important.

**Structured teaching**

There are various ways in which children can be helped to learn and there are debates about the advantages and disadvantages of different approaches. Some observers stress that for most children, progress is by natural learning through play and everyday social experience and therefore structured teaching programmes may not be an appropriate way to help children.

However, children with learning difficulties and delayed development often do not have the skills that are needed to learn in the more natural ways – for example, the motor skills to grasp or turn parts of toys, or the spoken language skills to join in a game or a conversation – so their ability to create their own learning experiences is reduced. In addition, they may need more examples of an association (for example hearing “cat” and seeing the cat) before they learn or more practice at a task (for example drinking from a cup, posting shapes into a box) before they master it. These extra learning opportunities will only happen if they are planned. The ideal compromise is to try to provide the extra learning experiences within ordinary daily activities and play as much as possible. The authors contributing to these modules believe that for children with Down syndrome to make progress as fast as they are able to, they need to experience good parenting and stimulat-
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Practicing everyday lives and they need some special structured teaching sessions each day.

The structured teaching sessions should try to combine natural learning approaches with more structured ones. In the natural learning situations, parents, teachers, brothers and sisters and grandparents use modelling, imitation and scaffolding, to show children how to do things and all these strategies will help children with Down syndrome. In addition, structured teaching will provide simplified and repeated opportunities to learn particular things, which can then be practised and mastered when they occur in everyday contexts. The dividing line between everyday learning and structured teaching is a fine one. Reading books together provides an ideal opportunity to teach new words and concepts to children, and can be used deliberately to increase learning opportunities by choosing books for vocabulary teaching, or shapes, colour or number. In other words book reading is being developed more consciously as a structured learning opportunity but it is a natural one as well.

Structured teaching may be taken a step further when the task to be learned is broken down into small steps and an errorless learning approach is used. Errorless learning simply means that the teacher prompts the child at each step as necessary, so that they successfully complete the task. This allows the child to learn how to succeed by imitation and practice rather than by trial and error. The teacher waits to allow the child to do the steps that he or she can without help but offers support before the child makes a mistake – a rather more deliberate form of natural scaffolding of children’s learning. The advantages of errorless learning are that the child can succeed every time and be praised for this and the child is practising the correct steps to success each time. If left alone, the child may not be able to work out how to do the task and fail every time. The disadvantage of errorless learning is that the child does not learn how to solve the problem or how to experiment and try new strategies. In the authors’ view, teaching and learning should be seen as a process over time and the skill of the successful teacher is in knowing when to provide maximum help using errorless learning techniques (at the start of learning a new task), how to slowly reduce that help (when the child can complete the practised task unaided) and to encourage some problem solving or ‘trial and error’ learning. The successful teacher will find similar tasks for the child to tackle, to generalise their learning to new situations and to ensure that the skill is practised, consolidated and understood.

Practice

Practice is an extremely important concept in children’s development. All learning involves being a novice and making mistakes, becoming successful at the task but only with thought and effort, and then mastering the task through practice until it becomes quick and easy to do successfully. At this stage the task has often become automated – that is, it can be carried out without the need to think or plan the action. Practice also continues to increase the skill and efficiency with which the task can be carried out.

It is easy to see how this applies to learning and perfecting motor skills such as drinking from a cup, using a knife and fork, dressing, writing, dancing, playing a musical instrument, playing tennis or driving a car, but it also applies to mental skills such as thinking, talking, and reading. As children learn to talk, the words that they produce only approximate to the sounds of adult words. As they practice, the words become more and more quickly...
and accurately spoken. As children learn to read, word recognition is effortful and each word has to be thought about. As children practice – read the same words over and over – word recognition becomes quick and automatic. Therefore, as children progress year by year, the improvement that they show is affected by the amount of practice that they have in the ordinary use of the skill (as in talking) or in the teaching and learning situations in preschool or school classroom. The faster children learn at the early stages of mastering a new skill, the more practice they have over the next weeks and months. Children who learn to talk with ease and start early, chatter away everyday from 14 or 15 months of age – getting a great deal of practice to improve their speech clarity, to put their thoughts into words and to be communication partners. Children who learn to read with ease in the first months in school, read more books and get much more reading practice than children who are struggling, leading to even bigger gaps between the progress of the fast and slower learners. It is the slower learners who need more practice to succeed and the usual effect of their difficulties is that they get less practice.

**Automatisation**

Automatisation of skills through practice leads to them being established in the brain as well learned and easy to access. Brain imaging studies can track this progress from effortful to automatic processing and the areas of the brain controlling automatised tasks may be different from those involved when learning a new task. Automatisation is important as automatised skills become readily available to support more complex activities. For example, knowing number words by rote makes counting tasks easier, and knowing sight words well makes reading for meaning easier.

**Family**

**Family issues**

In the authors’ experience, families have a number of concerns when they learn that their baby has Down syndrome. They are concerned for the baby and they are concerned for the family, as they often feel that their family life and future will now be changed as a result of becoming a family with a child with special needs.

There is now a growing body of research on the life of families with a member who has Down syndrome and this work is reviewed in detail in the module on the family. The research studies are largely reassuring, as they show that most families find the resources to cope with the special needs of the child with Down syndrome and still lead ordinary family lives. There is no evidence that brothers and sisters are negatively affected in the majority of families or that more marriages break down. This does not mean that there are not times of stress or difficulty, but most people do cope.

It helps to have friends, family and neighbours for emotional and practical help at times, so it is usually advantageous for parents to avoid social isolation. Many families report that they have found the support of other families with children with Down syndrome invaluable also, and joining parent groups a source of emotional and practical help. It also helps to have up-to-date and accurate information on the needs of the baby or young child and on the services available in the local community.
It is important that parents take care of themselves and each other. In the early days, the emotional shock and adjustment needed should be recognised. There are no rules here - some parents seem to adjust very quickly and others find the emotions take much longer to settle down. Usually the baby soon becomes a much loved individual, who is smiling and interacting and a joy. However, it is important to be able to express negative emotions and to be sad - adjustment is a process which takes time.

The demands of the new baby, and particularly all the advice and extra appointments, may be overwhelming and it is easy to become absorbed in early intervention activities and parent groups in the first few months. While some of this may be helpful, there is also the danger that it is exhausting for parents and taking time away from family life and other children, so it is important to keep a balance. As has been stressed already, the most important developmental and learning experiences for a baby with Down syndrome will come from being the much loved member of a happy, active family - and from doing all the things that the family does. The therapies and the lessons are the icing on the cake, they are not the main influence on development even though they will help. They certainly should not be allowed to take time away from family life and activities.

**Therapy and education services**

There are implications for service providers from all the issues discussed so far. The ideal service for babies and children with Down syndrome and their families should provide them with access to paediatric and health care, to physiotherapy and to speech and language therapy from the first year of life. Early intervention services should also be available from as early as possible, provided staff have training in counselling and emotional support as, if the service is offered at home, the home teacher will usually be a very significant positive source of information, practical advice and emotional support. Occupational therapy services will be valuable for some children with feeding and fine motor difficulties, if they are available.

By three years of age, children with Down syndrome should be able to join mainstream playgroups, preschools or kindergartens. Many children will benefit from extra support in these settings but some children will be able to cope without extra help. They will benefit greatly from the role models for social behaviour, play and language provided by the other children. Children with Down syndrome should not be ‘babied’ in these settings. They should be expected to conform to the routines and to behave as well as their peers. They should also access the same curriculum, and staff need to be clear that the children benefit from structured teaching and supported play.

**In conclusion**

This overview of development has highlighted the specific needs of children with Down syndrome and identified the areas in which they will benefit from specific help. Each of these areas, social development and behaviour, motor skills, speech and language, working memory, reading and writing, and number, are addressed in depth in separate modules - with an overview of current knowledge and a practical module on each topic. It is difficult to offer programmes of activity that take account of the wide range of individual differences in rates of progress in any group of children with Down syndrome. However, the specific modules in the *DSii Development and*
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Education series do try to take account of the variation. Children generally progress through the steps in development in any one area (for example, motor skills) in the same order - it is the rate of progress that varies. Some children will achieve all the targets in the practical modules by 5 years of age, but many children will achieve them later in their school years.

II. Health

Children with Down syndrome, like typically developing children, may be affected by any type of illness. However, it is recommended that all children and adults with Down syndrome have regular health checks to detect certain disorders as soon as possible. These systematic health checks should be carried out because people with Down syndrome tend to be affected by a number of disorders more commonly than other people. Of those disorders which have a higher prevalence in people with Down syndrome there are several which are of particular importance because they are relatively easy to diagnose and treat.

These disorders are as follows:-

- Disorders of hearing
- Disorders of vision
- Infections
- Disorders of thyroid function
- Constipation and diarrhoea
- Congenital disorders of the heart
- Atlanto-axial instability
- Sleep disturbances

Hearing disorders

Children with Down syndrome tend to have a significantly higher incidence of hearing problems than other groups and almost all surveys conclude that about 80% of them will have some problem with hearing. The importance of hearing cannot be overemphasised. The vast majority of children acquire language primarily by hearing what is being said by those around them and good hearing is involved in the development of speech and language as well as socialisation. These, as well as other factors, have a profound effect upon the general intellectual development of the child. The early detection and treatment of hearing deficits will be of great benefit to the child with Down syndrome.

Sounds, which are pressure waves in the air, travel along the external auditory canal and impinge upon the eardrum. This causes the eardrum to vibrate...
which, in turn produces movements in the bones or ossicles in the middle ear. These movements produce vibrations upon the oval window (a small membrane separating the middle ear from the inner ear) and, via the fluid in the inner ear, stimulate the hair cells of the cochlea differentially depending upon their various frequencies and pressures. It is at this stage that the information that is contained in these pressure changes is transformed (transduced) into nerve impulses which travel along the acoustic nerve via complex routes to the brainstem and brain where sound is perceived. Anything which interferes with any stage of this transfer chain will affect hearing.

The detection and diagnosis of hearing problems depends largely upon two factors:-

1. the routine screening of all young children as part of the prevailing public health program
2. the existence of a high level of suspicion on the part of carers that a hearing problem might be present.

Because of the high incidence of hearing problems in children with Down syndrome, and the fact that special testing techniques are sometimes needed, it is recommended that all of them should undergo appropriate hearing tests in a properly equipped and staffed audiology centre. The choice of which tests to use will depend upon circumstances and expert advice should be sought about this. The following descriptions are only a very short introduction to the subject.

**Tympanometry (or impedance or compliance testing)** is a commonly used test that records the manner in which the ear drum moves under the test conditions and this provides information about the function of the middle ear. It is a painless test but it does require a degree of co-operation from the child.

In the UK it is Government policy for all children to have their hearing evaluated shortly after birth with the Oto Emission Test (OAE). This test is purely passive in that it does not require any active participation from the subject and is, therefore, suitable for very young children. There are several versions of this test but they are all based on the detection and analysis of certain sounds which are produced by the inner ear. OAE is mainly useful for the detection of sensori-neural deafness, and other passive tests, which measure the way in which the eardrum moves, are used to detect middle ear problems.

**Visual Response Audiometry, VRA**, is now being used for older children. This test is one of a group of behavioural tests in which the child is conditioned to respond to sounds and is, therefore, useful for children who cannot be relied on to actively cooperate in responding to different types of sounds.

Where children are able to understand instructions to respond when they hear a sound, pure tone audiometry may be used. There are a number of versions of this technique, the principle of which is to test hearing by producing tones of known loudness and pitch in small increments. The child signals whenever he hears a specific tone and the responses are plotted on a chart – the audiogram.
The audiogram covers the range of frequencies (pitch) from 125 to 8000 Hz (cycles per second), and the range of loudness from zero to 100 dB (decibels).

The decibel is the standard unit of measurement for the intensity of sound, and is recorded on a logarithmic scale on the audiogram, separately for each ear.

A person with normal hearing will have a line from the lowest frequency tested, 125 Hz (cycles per second), to the highest frequency tested, 8000 Hz, at the level of about zero decibels (see Figure 4).

Figure 5 shows the audiogram from one ear of a person with a conductive hearing loss of about 35 dB.

The common causes of hearing difficulties in Down syndrome are:- wax in the external ear canal, ‘glue ear’, infection of the middle ear (otitis media) and sensori-neural hearing loss.

Wax in the external ear canal, particularly if it is old and hard, may interfere with hearing and should always be removed. Wax-softening eardrops should be tried in the first instance but if this procedure is not successful the wax will have to be removed by syringing or with the use of an appropriate instrument. These procedures should be performed by experienced professionals since the external ear canal is usually narrower in individuals with Down syndrome and this may make the procedure more difficult to do.

**Glue Ear** is one of the commonest conditions involving the ear and it has a particularly high incidence in children with Down syndrome, causing conductive hearing loss. In this condition a mucoid secretion accumulates in the middle ear and has the effect of reducing hearing levels. The situation for children with Down syndrome is different because the ‘glue’ is stickier, is less likely to drain away, and is more likely to become infected. The Eustachian tubes, which connect the middle ear to the upper part of the throat, are often not effective in allowing drainage from the middle ear.

There are three main techniques which are used in the treatment of glue ear.

The insertion of *grommets* in the ear drum allows the fluid to drain out of the middle ear into the external auditory canal. Grommets are tiny tubes with flanges at each end which are inserted through the eardrum and allow the glue to drain out. Tonsillectomy and/or adenoidectomy may also be helpful. This form of treatment is effective as long as the grommets remain in position in the eardrum. They have a tendency to become extruded (pushed out), remaining in place for about three to twelve months, but they are almost always helpful in allowing drainage and therefore improving hearing.

The disadvantages of extrusion can be avoided by creating an artificial perforation in the eardrum with a laser apparatus. These laser-produced perforations tend to heal within a few weeks but many clinicians feel that the procedure is very worthwhile.

*Microsuction* is a technique in which the fluid in the middle ear is sucked out through a thin needle inserted through the eardrum. This procedure...
usually has to be repeated several times but can be very effective. It has the advantage that there is no discharge into the external auditory canal to be dealt with.

The likelihood of Middle Ear Infections in children with Down syndrome is considerably greater than in any comparable group of children. The reasons for this are the special problems of glue ear and the fact that individuals with Down syndrome are more susceptible to infections of all kinds. The treatment of middle ear infections usually involves the use of antibiotics and may also necessitate one of the interventions listed above for glue ear.

There is a view among some otologists that grommets should not be used because of the narrow external auditory canal found in children with Down syndrome, because they are often extruded and because continual replacement may scar the ear drum. The authors, and others, disagree with this view because they feel that the benefits of improved hearing upon language development and upon socialisation as well as on general intellectual development and self-confidence far outweigh the possible difficulties associated with grommets. If grommets are not appropriate for a particular child, hearing aids may be offered for conductive loss.

Sensori-neural hearing loss is a poorly understood set of conditions in which the inner ear or cochlea malfunctions. The phrase is sometimes used to include problems in other parts of the central nervous system as well. It may be constitutional or develop in later life and the higher tones are mostly affected. This type of hearing loss may have a serious effect on understanding since it is these frequencies which give speech most of its intelligibility. This type of hearing loss is often overlooked in the early stages because these children do not always behave as if they are deaf. They respond to sounds of many different kinds but what they hear is a type of low frequency rumble containing little real information. Those who can lip-read may sometimes be able to communicate to some extent.

There is no cure in this group of conditions and those who benefit from the use of hearing aids continue to depend on them indefinitely.

The suggested program for routine audiology is firstly at about nine months of age and annually until ten years of age. After the age of ten years testing every two years is considered sufficient.

There are a number of sophisticated techniques available which test different aspects of the hearing system but it is important to remember that the only way to be sure that a child has proper sound perception is by their behavioural response to purely aural information.

Hearing Aids may be needed in a proportion of people with Down syndrome and the situation has now improved in that hearing aids are now very much more sophisticated than they used to be.

The enormous processing power of digital chips is now being used in hearing aids so that the specific requirements of children with different types of hearing loss can be compensated for much more accurately.

![Figure 6. Hearing ranges for speech sounds](image_url)
Getting used to wearing an aid may be a difficult problem in some cases. Children need to learn that the aid is actually helpful and a period of training may be necessary. This is often best started in a quiet room with no distracting noises so that the child can appreciate the improvement in the understanding of speech. They may then be gradually introduced into more open environments. In more difficult cases a radio-link may be helpful. This consists of a combined aid and radio receiver for the child and a transmitter-microphone for the carer. This apparatus almost totally excludes extraneous noise and allows the child to appreciate the use of aiding more easily. It is obviously very important not to give up in the face of difficulties, but to be persistent in attaining success.

Although hearing losses of up to 25 dB are usually not considered to be serious in typically developing children, there is evidence to suggest that even mild hearing loss has a deleterious effect on educational, emotional and language development in children who have no disorders other than hearing loss.

These data lend powerful support to the view that mild hearing loss is likely to have an even greater effect on children with Down syndrome.

Signing is almost always helpful in the particular situation where language development is being impeded by hearing difficulties. The advantage of this strategy is that language development can progress even in the presence of hearing difficulties.

**Disorders of vision**

There are a number of eye disorders which are of special relevance in Down syndrome but, apart from infections of the eyelid and conjunctiva, the commonest and most important are disorders which distort the image upon the retina. The majority of these are errors of refraction, i.e. short and long sightedness and astigmatism.

Because these errors of refraction are so common in individuals with Down syndrome it is important to have a high index of suspicion that they may be present. It is probable that children with Down syndrome rely on visual information to a relatively larger extent than other children. If this is so it means that vision is, relatively, even more important than it would normally be.

Testing of visual function should be carried out routinely every year in all children with Down syndrome until the age of ten years and every two years afterwards and as soon as possible if there is any clue in the behaviour of the child which could be accounted for by deteriorating vision. It is possible to test vision in virtually all children, even those who are very young and/or who cannot speak.

Fortunately almost all errors of refraction are treatable with the use of spectacles. New developments in lens manufacture have made lightweight plastic lenses available, and for those whose who have a very flat nasal bridge, double bridge pieces can be very helpful. Elasticised bands which attach to the ear pieces, such as are used by sportsmen can be useful in preventing spectacles from falling off. It is important that glasses be kept clean at all times, so that the child is always aware that they really do made the world around them easier to see.
A spare pair of glasses should always be available – it is not worth the disruption of waiting for new pair if the current one is lost or damaged.

The employment of behavioural techniques may be necessary if the child refuses to wear the spectacles. In any event it is useful to create situations where the child realises that vision is improved with use of spectacles.

**Disorders of thyroid function**

The thyroid gland is a shield-shaped gland situated at the base of the neck. It produces three main hormones; thyroxine, triiodothyronine and calcitonin. Disorders of thyroid function (excluding calcitonin, which will not be dealt with here) are amongst the commonest of all endocrine disorders. In the United Kingdom as a whole the prevalence of hypothyroidism is 1.4% in females and 0.1% in males. The prevalence in individuals with Down syndrome, however, is considerably higher. Thyroxine (T4) and triiodothyronine (T3) control many aspects of development and metabolism and are essential for proper development and function.

Of the many types of thyroid disorder which may occur, much the most frequent is hypothyroidism - underactivity of thyroid function - and the prevalence of this condition in people with Down syndrome is considerably higher than in the population as a whole.

The main clinical features of hypothyroidism (under-functioning of the thyroid gland), are slowness, both physical and mental, dry hair, thickening of the skin, deepening of the voice and weight gain. In addition the following symptoms are also found; intolerance of cold, slow pulse, constipation, slowed growth velocity, deteriorating performance at school, delayed or absent puberty, and a large variety of mental problems.

These signs and symptoms vary a great deal between individuals both in degree and in the particular combinations expressed. The situation is complicated by the fact that the signs of hypothyroidism, which are often insidious in their onset, are frequently attributed to Down syndrome itself.

The clinical features of hypothyroidism on their own are not sufficient to make the diagnosis; this can only be made with certainty by the laboratory measurement of thyroid stimulating hormone (TSH) and the thyroid hormones.

TSH is a hormone which is produced by the pituitary gland and which stimulates the thyroid gland to produce T4 and T3. This hormone is usually used as an index of thyroid function because its concentration increases when the level of T4 and T3 falls. However, because the level of TSH may be sometimes higher than normal in the presence of normal thyroid function in people with Down syndrome, it is considered advisable to measure T4, T3 as well as TSH whenever thyroid function tests (TFTs) are performed. Because of the great importance of not missing a diagnosis of hypothyroidism all screening protocols advise performing TFTs periodically throughout life. The recommended intervals vary from once every five years to annual testing, the most popular suggestion being two-yearly testing. Even if the symptoms of a disorder can be explained in other ways, it is still useful to perform TFTs as part of the general investigation of the problem because of its relative commonness and the possibility of multiple diagnosis.
Treatment

Once the diagnosis of hypothyroidism has been made, the treatment consists of the administration of tablets containing T4 by mouth. The thyroxine contained in these tablets is identical to the thyroxine produced by the human thyroid gland and if the dosage is properly monitored should not produce problems.

After the initiation of treatment, follow-up visits should be held at three-monthly intervals until the appropriate dose has been established and every six to twelve months thereafter. Growth and weight should be measured at regular intervals and some estimate of cognitive progress made. It is also useful to try to obtain some idea of the general state of well being of the patient.

As children grow and their body weight increases the need for T4 will increase and it will be necessary to adjust the dose guided by the results of the TFTs.

Rarely it is found that the treatment is stopped, either because it is felt that the patient is ‘cured’ or for other reasons. It is, therefore, important to impress upon all those involved that the treatment of hypothyroidism is lifelong, that proper monitoring is necessary and supplies of T4 are always kept available.

The treatment of hypothyroidism is not difficult, is cheap, has no side effects and, because it is perfect replacement therapy, produces ideal results.

Infection in people with Down syndrome

The increased incidence of infections in people with Down syndrome is very well documented. Until the nineteen fifties it was the leading case of morbidity and mortality in Down syndrome.

Respiratory infections are particularly common, especially during the first five years of life, and infections of the skin and the bladder are also common.

The great increase in longevity in people with Down syndrome is primarily due to modern methods of treating infection. There is evidence that people with Down syndrome have this increased susceptibility to infection because their immune systems have some abnormalities. Fortunately this does not mean that they do not respond to immunisation procedures or antibiotics, but it does mean that they are prone to more frequent infections than control groups and that they are sometimes more difficult to treat.

The implications of this increased susceptibility is that antibiotics tend to be needed more frequently in people with Down syndrome and it is likely that they will need to be used earlier in the course of an infection as well.

Immunisations ought to be carried out in the normal way but it is sometimes necessary to ensure that the antibody response is adequate. Immunisation against hepatitis B is now commonly included with the usual list of childhood immunisations since the incidence seems to be higher in people with Down syndrome. This disease is highly infectious and a good case could be made for everyone to be immunised against it.

The presence of occult, or hidden infections should be suspected if a child with Down syndrome seems below par for no obvious reason. Common
sites for such infections are in the bladder, the throat and tonsils, the teeth, the middle ear and the skin.

Generally, problems with infections tend to decrease as the person with Down syndrome grows older.

**Gastro-intestinal system**

People with Down syndrome are more likely to have more problems with the stomach and intestines than other comparable groups of people. One of the commonest of these is constipation. If the constipation is very serious the child should, preferably, be investigated by a paediatric gastroenterologist since there are some rather serious conditions of the gut which present in this way. If special investigations reveal no obvious reason for the constipation it may then be managed symptomatically.

Occasionally the lower part of the colon becomes greatly distended and chronically filled with faeces. This can be a difficult problem to deal with and emptying the lower colon can be difficult. The help of a physician experienced in techniques for emptying the colon may be needed.

Even if the child has a good mixed diet and has an adequate fluid intake, constipation may continue to be a problem and the management then usually consists of a combination of habit training and laxatives.

The use of laxatives should be closely monitored as to dosage and frequency since these details often determine the difference between success and failure.

**Cardio-vascular system**

Although incidence figures vary, it is generally accepted that about 50% of babies born with Down syndrome will have a disorder of the heart. These congenital cardiac disorders vary enormously in type and severity. Many of them are relatively mild and do not need surgical intervention, some are fairly easy to deal with, while a proportion are serious and necessitate complex surgery.

Because of the high incidence of congenital cardiac defects most paediatric departments have screening programs for newborn children with Down syndrome. The use of ultrasound in screening programs has made the detection of cardiac abnormalities easier and has had the effect of allowing earlier and more effective treatment.

The diagnosis and treatment of cardiac disorders is highly specialised and is the province of the paediatric cardiologist and paediatric cardiac surgeon.

Detailed information on the different types of cardiac disorders and their treatment as well as support are available from the Down’s Heart Group.

**Atlanto-axial instability**

Many parents and carers are advised not to allow children with Down syndrome to engage in certain sports such as trampolining and forward rolling. This advice is based on the view that people with Down syndrome are more likely to have difficulties in the top part of the spinal column.

Some understanding of the anatomy of the area may help to clarify some of the issues (see Figures 7 and 8).
The first vertebra of the spinal column is called the ‘atlas’ or C1 (1st cervical vertebra). It is a roughly circular bone with two areas on its upper surface which support the skull and the atlas, in turn, rests upon the second neck vertebra which is called the ‘axis’ or C2.

The axis has a projection, called the ‘odontoid process’, which projects upwards inside the circle of the atlas. This bony ring, therefore, contains, among other things, the odontoid process and the upper part of the spinal cord behind it.

If the anatomy of this area is altered so that the odontoid process is pushed backward it could then press upon the spinal cord and damage it.

This occurrence is very rare in people with Down syndrome and the mechanisms are still not properly understood but, at present, some organisations such as the Special Olympic Committee require that people with Down syndrome have been tested for evidence of ‘atlanto-axial instability’ (a-a) as a condition for being accepted for the Special Olympics.

The test for ‘a-a instability’ consists of taking x-rays of the neck in several different positions and measuring the distances between various parts of the vertebrae and the spinal cord.

In 1986 the Department of Health of the United Kingdom recommended that people with Down syndrome should have their necks x-rayed before engaging in vigorous sporting activity.

However it later became evident that x-ray examination for ‘a-a instability’ was not a reliable way of predicting whether there was an increased likelihood of spinal damage in those people who were diagnosed as having ‘a-a instability’ and the original recommendations of the Department of Health that these x-rays should be carried out were withdrawn in 1995.

‘Atlanto-axial instability’ remains a controversial issue and although damage to the spinal cord is rare, it is important to point out that when such damage does occur it seldom does so without warning.

The signs of upper spinal cord compression usually start with weakness, new difficulties in walking, not lifting the feet properly and unsteadiness. Pain or discomfort in the neck may occur and sometimes the neck may be held in unusual positions.

Bladder and bowel function may be affected and problems with hand and arm function may be later signs.

When possible warning signs do appear it is essential that competent medical
An overview of the development of infants with Down syndrome

intervention is sought as soon as possible in order to establish a diagnosis and institute appropriate treatment.

It is sometimes suggested that a supportive neck collar be worn, especially by people with Down syndrome, if they have pain or discomfort in the neck. This may do more harm than good because supporting the head in this way relieves the neck muscles of the normal exercise they continually perform with the result that they become weak.

Virtually all joints need properly functioning musculature to ensure that they function well and it is, therefore, important that all muscles should maintain their tone and strength with adequate exercise.

The view of many Down syndrome medical advice groups is that there is no good evidence that any form of exercise carries an additional risk for people with Down syndrome.

Sleep and sleep disturbance

Sleep disturbances are common in children with Down syndrome and parents need to be alert to the different types of sleep difficulties, as some are of physical origin and some are behavioural. Most children with Down syndrome seem to be restless sleepers and move all over the cot or bed. The significance of this is not known. However, some children have restless or disturbed sleep as a result of obstructed or partially obstructed airways. Enlarged tonsils, adenoids and tongues may contribute to obstruction. If a child is a noisy breather, and restless or waking frequently, it is wise to get an assessment. Sleep apnoea - short periods when breathing temporarily stops - occurs for a minority of children. The whole area of breathing related sleep disturbance needs more research. There is the possibility that it affects development and daytime behaviour.

Children may have disturbed sleep for behavioural reasons. For example, reluctance to go to bed, night waking and early waking can be habits, and they will respond to behavioural management strategies.

It is important to resolve sleep difficulties as poor sleep has a debilitating effect on the child and the whole family.

Monitoring developmental progress

A number of Down syndrome medical interest groups as well as other organisations provide information and record charts which are particularly helpful in monitoring the health of children with Down syndrome.

These include charts illustrating the changes in height and weight with age, developmental milestones and record charts for health checks and their results. These charts help to ensure that health checks are carried out at the appropriate times. These pages are meant to be added to the existing records in the child’s Personal Child Health Record Book (PCHR).

In the UK these can be obtained from: Down’s Syndrome Medical Interest Group, Children’s Centre, City Hospital Campus, Hucknall Road, Nottingham, NG5 1PB. Email: info@dsmig.org.uk http://www.dsmig.org.uk

Excellent information, and videos on heart defects, can be obtained from: Down’s Heart Group, 17 Cantilupe Close, Eaton Bray, Dunstable, Bedfordshire, LU6 2EA. Email: Downs_Heart_Group@msn.com http://www.downs-heart.downsnet.org/


The most informative website providing information on health and medical issues is that provided by Len Leshin, a paediatrician and father of a child with Down syndrome, at: [http://www.ds-health.com/](http://www.ds-health.com/)
# Milestones for children with Down syndrome

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Children with Down syndrome</th>
<th>Typically developing children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Balances head and holds it steady when swayed</td>
<td>5m</td>
<td>3m to 8.5m</td>
</tr>
<tr>
<td>Rolls from side to back</td>
<td>5m</td>
<td>3m to 9m</td>
</tr>
<tr>
<td>Rolls from stomach to back</td>
<td>6m</td>
<td>5m to 12m</td>
</tr>
<tr>
<td>Supports body on arms, lifts head and chest when lying on stomach</td>
<td>6m</td>
<td>3m to 10m</td>
</tr>
<tr>
<td>Reaches one arm forward when lying on stomach</td>
<td>6m</td>
<td>5m to 10m</td>
</tr>
<tr>
<td>Sits with support</td>
<td>7m</td>
<td>5m to 9m</td>
</tr>
<tr>
<td>Hand to foot play</td>
<td>7m</td>
<td>4m to 10m</td>
</tr>
<tr>
<td>Rolls from back to stomach</td>
<td>7m</td>
<td>5m to 9m</td>
</tr>
<tr>
<td>Rolls over</td>
<td>8m</td>
<td>4m to 12m</td>
</tr>
<tr>
<td>Moves around his/her own axis while sitting on floor</td>
<td>8m</td>
<td>5m to 13m</td>
</tr>
<tr>
<td>Sits while supported by own arms</td>
<td>8m</td>
<td>5m to 15m</td>
</tr>
<tr>
<td>Sits in high chair</td>
<td>9m</td>
<td>6m to 15m</td>
</tr>
<tr>
<td>Sits without support for one minute or more</td>
<td>9m</td>
<td>6m to 16m</td>
</tr>
<tr>
<td>Crawls</td>
<td>14m</td>
<td>9m to 19m</td>
</tr>
<tr>
<td>Sits steadily for 10 minutes or more and is well balanced</td>
<td>11m</td>
<td>8.5m to 15.5m</td>
</tr>
<tr>
<td>Changes from sitting to standing position</td>
<td>13m</td>
<td>8m to 17m</td>
</tr>
</tbody>
</table>
### GROSS MOTOR SKILLS

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Children with Down syndrome</th>
<th>Typically developing children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Crawl with stomach lifted from the floor</td>
<td>14m</td>
<td>10m to 20m</td>
</tr>
<tr>
<td>Pulls to stand using furniture</td>
<td>15m</td>
<td>8m to 26m</td>
</tr>
<tr>
<td>Walks with support</td>
<td>16m</td>
<td>6m to 30m</td>
</tr>
<tr>
<td>Stands alone</td>
<td>18m</td>
<td>12m to 38m</td>
</tr>
<tr>
<td>Climbs up a flight of stairs</td>
<td>20m</td>
<td>12m to 28m</td>
</tr>
<tr>
<td>Walks 10 feet with a push toy</td>
<td>22m</td>
<td>16m to 30m</td>
</tr>
<tr>
<td>Walks alone</td>
<td>23m</td>
<td>13m to 48m</td>
</tr>
<tr>
<td>Walks upstairs with help</td>
<td>30m</td>
<td>20m to 48m</td>
</tr>
<tr>
<td>Walks downstairs with help</td>
<td>36m</td>
<td>24m to 60m+</td>
</tr>
<tr>
<td>Runs</td>
<td>around 4 years</td>
<td></td>
</tr>
<tr>
<td>Walks up stairs holding the rail alternating feet</td>
<td>56m</td>
<td>(40m to 66m)</td>
</tr>
<tr>
<td>Jumps on the spot</td>
<td>4 to 5 years</td>
<td></td>
</tr>
<tr>
<td>Rides a tricycle 15 feet</td>
<td>61m</td>
<td>(50m to 72m)</td>
</tr>
<tr>
<td>Walks down stairs holding the rail alternating feet</td>
<td>81m (21m)</td>
<td>(60m to 96m)</td>
</tr>
<tr>
<td>ACTIVITY</td>
<td>Children with Down syndrome</td>
<td>Typically developing children</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Smiles when touched and talked to</td>
<td>2m</td>
<td>1.5 to 4m</td>
</tr>
<tr>
<td>Smiles spontaneously</td>
<td>3m</td>
<td>2m to 6m</td>
</tr>
<tr>
<td>Recognises mother/father</td>
<td>3.5m</td>
<td>3m to 6m</td>
</tr>
<tr>
<td>Approaches image in mirror</td>
<td>6.5m</td>
<td>4m to 10m</td>
</tr>
<tr>
<td>Takes solids well</td>
<td>8m</td>
<td>5m to 18m</td>
</tr>
<tr>
<td>Feeds self with biscuit</td>
<td>10m</td>
<td>6m to 14m</td>
</tr>
<tr>
<td>Plays pat-a-cake, peep-bo games</td>
<td>11m</td>
<td>9m to 16m</td>
</tr>
<tr>
<td>Holds up arms and legs when getting dressed and undressed</td>
<td>15m</td>
<td>12m to 20m</td>
</tr>
<tr>
<td>Drinks from a cup</td>
<td>20m</td>
<td>12m to 30m</td>
</tr>
<tr>
<td>Uses spoon or fork</td>
<td>20m</td>
<td>12m to 36m</td>
</tr>
<tr>
<td>Urine control during the day</td>
<td>36m</td>
<td>18m to 50m+</td>
</tr>
<tr>
<td>Plays social/interacting games</td>
<td>3.5 to 4.5 years</td>
<td></td>
</tr>
<tr>
<td>Bowel control</td>
<td>36m</td>
<td>20m to 60m+</td>
</tr>
<tr>
<td>Dresses self partially (not buttons/laces)</td>
<td>4 to 5 years</td>
<td></td>
</tr>
<tr>
<td>Uses toilet or potty without help (using a special step)</td>
<td>4 to 5 years</td>
<td></td>
</tr>
<tr>
<td>ACTIVITY</td>
<td>Children with Down syndrome</td>
<td>Typically developing children</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-----------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Follows object with eyes, in circle</td>
<td>3m</td>
<td>1.5m to 6m</td>
</tr>
<tr>
<td>Grasps dangling ring</td>
<td>6m</td>
<td>4m to 11m</td>
</tr>
<tr>
<td>Removes towel from eyes (during play)</td>
<td>8m</td>
<td>5m to 13m</td>
</tr>
<tr>
<td>Looks for an object which disappears out of view</td>
<td>8m</td>
<td>5m to 13m</td>
</tr>
<tr>
<td>Lets go of one object in order to pick up another</td>
<td>8m</td>
<td>5m to 11m</td>
</tr>
<tr>
<td>Passes object from hand to hand</td>
<td>8m</td>
<td>6m to 12m</td>
</tr>
<tr>
<td>Imitates movements</td>
<td>11m</td>
<td>8 to 17m</td>
</tr>
<tr>
<td>Shakes rattle to make a sound</td>
<td>11m</td>
<td>8 to 17m</td>
</tr>
<tr>
<td>Pulls string to attain toy</td>
<td>11.5m</td>
<td>7m to 17m</td>
</tr>
<tr>
<td>Picks up object from a box</td>
<td>12m</td>
<td>9m to 17m</td>
</tr>
<tr>
<td>Finds objects hidden under cloth</td>
<td>13m</td>
<td>9m to 21m</td>
</tr>
<tr>
<td>Uses index finger to explore objects</td>
<td>13m</td>
<td>8m to 22m</td>
</tr>
<tr>
<td>Claps hands</td>
<td>13m</td>
<td>9m to 18m</td>
</tr>
<tr>
<td>Opens box to find a toy</td>
<td>14m</td>
<td>11m to 17m</td>
</tr>
<tr>
<td>Rolls/catches ball</td>
<td>14m</td>
<td>10m to 19m</td>
</tr>
<tr>
<td>Makes marks on paper with crayon</td>
<td>14m</td>
<td>10m to 27m</td>
</tr>
<tr>
<td>Attempts to imitate a scribble</td>
<td>15.5m</td>
<td>10m to 21m</td>
</tr>
<tr>
<td>Puts cube in cup</td>
<td>16.5m</td>
<td>10m to 24m</td>
</tr>
</tbody>
</table>
### FINE MOTOR AND ADAPTIVE

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Children with Down syndrome</th>
<th>Typically developing children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Puts 3 or more objects into cup or box</td>
<td>19m</td>
<td>12m to 34m</td>
</tr>
<tr>
<td>Picks up an object size of a currant using thumb and forefinger only</td>
<td>20m</td>
<td>12m to 36m</td>
</tr>
<tr>
<td>Builds a tower of two 1&quot; cubes</td>
<td>20m</td>
<td>14m to 32m</td>
</tr>
<tr>
<td>Puts a peg in peg-board two or more times</td>
<td>23m</td>
<td>17m to 36m</td>
</tr>
</tbody>
</table>

### COMMUNICATION ACTIVITIES

<table>
<thead>
<tr>
<th>ACTIVITY</th>
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<th>Typically developing children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Reacts to sounds</td>
<td>1m</td>
<td>0.5m to 1.5m</td>
</tr>
<tr>
<td>Vocalises to smile and talk</td>
<td>4m</td>
<td>1.5m to 8.5m</td>
</tr>
<tr>
<td>Shows satisfaction in social interaction</td>
<td>6m</td>
<td>5m to 9m</td>
</tr>
<tr>
<td>Gains attention by making sound variations (not crying)</td>
<td>7m</td>
<td>5m to 12m</td>
</tr>
<tr>
<td>Turns to sound of voice</td>
<td>6m</td>
<td>3m to 8m</td>
</tr>
<tr>
<td>Reacts appropriately to signal gestures (come up, look)</td>
<td>8m</td>
<td>6m to 13m</td>
</tr>
<tr>
<td>Say da-da, ma-ma</td>
<td>11m</td>
<td>7m to 18m</td>
</tr>
<tr>
<td>Performative communication</td>
<td>11m</td>
<td>8m to 18m</td>
</tr>
<tr>
<td>Imitates sound</td>
<td>11m</td>
<td>7m to 18m</td>
</tr>
</tbody>
</table>
### Communication Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Children with Down Syndrome</th>
<th>Typically developing children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average age</td>
<td>Range</td>
</tr>
<tr>
<td>Responds to familiar words</td>
<td>13m</td>
<td>10m to 18m</td>
</tr>
<tr>
<td>Responds to familiar words by gestures, etc.</td>
<td>13.5m</td>
<td>10m to 18m</td>
</tr>
<tr>
<td>Responds to ‘no’</td>
<td>14m</td>
<td>11m to 24m</td>
</tr>
<tr>
<td>Responds to simple verbal instructions</td>
<td>16m</td>
<td>12m to 24m</td>
</tr>
<tr>
<td>Points when requested to 3 body parts (eye,</td>
<td>17m</td>
<td>13m to 25m</td>
</tr>
<tr>
<td>nose, mouth)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jabbers expressively</td>
<td>18m</td>
<td>12m to 30m</td>
</tr>
<tr>
<td>Says first word(s)</td>
<td>18m</td>
<td>13m to 36m</td>
</tr>
<tr>
<td>Shows needs by gestures</td>
<td>22m</td>
<td>14m to 30m</td>
</tr>
<tr>
<td>Says 2 words</td>
<td>22m</td>
<td>15.5m to 30m</td>
</tr>
<tr>
<td>A few two word sentences</td>
<td>30m</td>
<td>18m to 60m+</td>
</tr>
<tr>
<td>Uses words spontaneously and to communicate</td>
<td>1.5 to 6 years</td>
<td></td>
</tr>
</tbody>
</table>

These milestones have been adapted from:

Hanson, M.J. (1987) *Teaching the Infant with Down syndrome*. Austin, Texas: Pro-Ed. P. 27
An overview of the development of infants with Down syndrome

References


