

Early Support

Helping every child succeed

How to use the Journal



Contents

Welcome	2
What is it and what's it for?	3
Supporting effective early intervention	3
Using the Journal with other people	4
One set of material to use with different professionals	4
How should the Journal be used?	5
Do it your way	5
Getting started	6
How often?	6
Finding your way around the materials	7
Areas of development	7
Developmental steps	8
Using the Journal	9
Recording progress using the Developmental steps	9
Notes or queries	10
Summary sheets	14
The Developmental profile – getting an overview	14
Worries or concerns	17
Special achievements and things to celebrate	17
Glossary	18
Age norms and expectations	19
Babies and children with Down syndrome	19
Guidelines for typically developing children	20
Guidelines for children with Down syndrome	21
Other resources for families and professionals	24
How the material was developed	25



What parents say

'A very good, parent-friendly document.'

'An excellent document for parents to follow as a guide for development of babies and children with Down syndrome. The Steps help parents guide their child in many areas of development.'

'You can immediately see where your child is up to, and what goals to set.'

'I'm presently in the middle of the statement process for my 4 year old son with Down syndrome. I could write the 'Parents written contribution' more confidently and fully as I could see – at a glance – his strengths and weaknesses. I could also evaluate easily his areas of special educational needs and say how I'd like these to be addressed.'

'The Developmental Journal is like a treasure – I'm discovering so much about what my child has achieved (a pleasant surprise) and becoming aware of the many skills emerging that I need to follow through.'

The Early Support *Developmental Journal for babies and children with Down syndrome* has been written to help parents and the professionals who work with them.

We therefore consulted with parents across England and with professionals as the material developed, over a two-year period. This collaborative process was essential to the development of the material and we would like to thank everyone who contributed or made suggestions for how the Journal could be improved.

Welcome

This Journal is to help parents and families record and celebrate children's development, strengths and achievements through the preschool years, and to identify any areas of difficulty that may need closer attention. It's for you and your child.

Celebrating and supporting progress

When a baby is born with Down syndrome, parents often say they don't know what to expect – they're not sure how their baby's progress may be affected, or what to do to help. Keeping this Journal will help you to see how your child is progressing and to understand the patterns of development that professionals are looking for and asking you to encourage through therapy and other activities. We hope it will also help you to see where a child with Down syndrome is likely to have more difficulty than other children and may need some extra help.

Start when you feel ready

The Journal allows you to record your child's development from birth through the preschool years. You can start using it whenever you feel that the material would be helpful to you.

Use it with other materials

The Developmental Journal is designed to be used with the Early Support Information for parents booklet on *Down syndrome*. The content of these two publications has been written to work together. The Journal is designed to help you support and record your child's progress. The Information for parents booklet has additional detail on the development of children with Down syndrome, the professionals who can help you and where you can find extra information and practical resources. Both these publications can be used alongside other Early Support materials.

Read more about other **Early Support** materials and how to get hold of them at the end of the booklet



What is it and what's it for?

The *Developmental Journal for babies and children with Down syndrome* is a tool to help you track and understand development in your child and to share that information with other people.

It:

- helps you record and celebrate change, achievements and progress in the early years
- helps you understand the significance of what your child is doing now, what they will do next and how you can support their progress
- provides an on-going record of your child's achievements, progress and development as they learn to do new things
- recognises the important information about your child that you have and makes it easier for you to share that information with other people
- helps professionals work in partnership with families by providing a shared basis for discussion
- supports effective early intervention services by improving everyone's understanding of the developmental processes involved.

Supporting effective early intervention

Most babies with Down syndrome are identified during pregnancy or soon after birth. This early identification creates opportunity because it enables services and support to be put in place for babies right from the start. Good services from early on benefit babies and families – both at the beginning and in the longer term.

A record of your child's individual progress including strengths, achievements and needs, helps you and those supporting you to devise an individual early intervention programme that works for you and for your child. Small developments happen every day when professionals aren't there to see – but you are! Keeping a record of achievements helps you to discuss them with other people and to understand more about how your child learns.

Using the Journal with other people

The Journal comes alive when you talk about it with other people. You can discuss it with anyone you like – your family, carers, therapists, teachers and other professionals.

One set of material to use with different professionals

Families sometimes say the different words used by different professionals are confusing for them. We hope that the Developmental Journal will help everyone 'talk the same language' by providing a single, shared frame of reference. Families can share progress and concerns with all the professionals they meet and be confident everyone is using the same information. This should make asking questions at appointments easier and ensure that families feel better-informed and that they are listened to. The Journal promotes equal partnership between families and professionals and joint working on behalf of the child.

If you're a parent or carer, the Developmental Journal can help you to:

- celebrate and record the achievements your child makes – large and small
- recognise the importance of what your child is doing and of each new thing they learn to do
- share your observations with other people, including the professionals working with you
- ask questions about progress
- be clear about what sorts of things everyone is expecting your child to do next
- have a clearer idea about what you can do to help
- have an up-to-date, accessible record of your child's development which can be copied, given to professionals and used to support discussion about your child at appointments or when reports need to be written.



If you're a professional, the Developmental Journal is designed to:

- provide a consistent, standard way to record progress that covers all the relevant areas of development
- identify aspects of development which might need to be followed up further
- support your discussions with families and other professionals
- help you work in partnership with families
- help you give better advice.

How should the Journal be used?

Do it your way

There are a number of different ways in which you may decide to use the Developmental Journal. You may want to:

- fill in the record on your own and then share it with professionals later
- ask professionals to discuss the Journal with you every now and again and fill it in together
- use it to talk with professionals about how your child is doing, but not fill it in – some people like to ask someone else to fill it in for them.

The whole Journal can seem a bit overwhelming and families have different ideas about how they want to use it. This is fine – please **use it in whatever way you find most helpful.**

We've provided material at two levels of detail, so you can choose how much information you want to use. You may feel differently about this at different times – sometimes a quicker version will be OK, while at other times you may want to look at things in more detail.

Getting started

If you begin using the Journal early, in the first few months of your baby's life, start at the beginning. You'll soon become familiar with how to record new achievements.

If you start using the Journal when your child is a bit older, you don't have to go back and fill in all the earlier material. For older children, we suggest using the **Summary sheets** to help you find a good starting point. Think of the things your child is currently able to do and a few new things they've learnt to do for the first time recently. Flick through the **Summary sheets** until you find something that describes what you're thinking about. This should guide you towards the material that's most relevant to your child's current stage of development and indicate the best place to start keeping a record.

You'll probably find that your child is developing skills that fall across several different **Steps** at the same time – for example, at any given time a child may be developing **motor** skills in **Step 2**, **communication** skills in **Step 3** and **self-help** skills in **Step 4**. So flick backwards and forwards to look at the different sections in a number of different **Steps** to find your way around and to get a general idea of where you are, before you start to write things down.

How often?

Most parents say they prefer to fill in the Developmental Journal regularly so they don't forget all the different little things that their child has learnt to do. We recommend filling it in every few weeks when your child is very young, and then filling it out on a monthly or two monthly basis, as skills become more complex and take longer to learn.

Filling the Developmental Journal in regularly ensures any areas of difficulty are identified as they emerge and allows everyone involved with your child to target their interventions to provide support in these areas.



Finding your way around the materials

Areas of development

The Developmental Journal describes children's development under five headings:

Communication

Communication describes the many different ways that your child interacts with other people, such as looking, pointing, smiling and talking. It includes how your child pays attention to other people and listens to them, as well as how they understand and use language themselves.

Social-emotional

Social-emotional development focuses on how children learn who they are, what feelings they have, how to behave and how to develop relationships.

Cognition and play

Cognition and play looks at the ways your child develops and learns through playing, how they develop thinking and reasoning skills, and how they process and remember information.

Motor and sensory

Motor and sensory development focuses on how your child develops gross and fine movement abilities and uses senses and movement to explore the world.

Self-help

Self-help looks at how your child develops practical independence and learns skills that help with feeding, sleeping, washing, toileting, and dressing.

While it's helpful to chart progress under these five headings, in real life, progress in one area influences how a child learns everything else, so it's helpful to think about your child's progress across all five areas. We have divided the Journal into [Steps](#) to help you to do this.

Children with Down syndrome often show more variation in their progress in different **areas of development** than other children, so expect to see faster progress in some areas than others. The way the Journal is organised highlights where this is the case and will help you to see more clearly exactly where your child needs extra help.

It's important to realise that these five **areas of development** are what professionals use to describe children's progress. There will be many other things your child is doing and learning that will be equally important for you, if not more so – for example, the types of music or food they like and what makes them laugh. Observations of this kind can also be recorded in the Journal. This information can often be particularly helpful for professionals meeting your child for the first time or as they try to understand your child's particular characteristics.

Developmental steps

The Developmental Journal is presented in the form of 11 **Developmental steps**, beginning in the first weeks of life. The skills and behaviours in each **Step** describe what an average, typically developing child achieves in each of the five **areas of development** at that stage in development. Most babies and young children with Down syndrome can achieve all of these behaviours, but may take longer to do so than other children.

Steps 1 and 2 only have been simplified into three areas of development: **engagement and interaction with others**; **sensory-motor development and play** and **self-help**. When children are very young, behaviours tend to be more integrated and difficult to separate out. For example, a young baby reaching out to grasp a toy is using **sensory, motor and cognitive** skills. The simplified areas of development in the first two **Steps** are designed to reflect the integrated nature of early development.

There are also **Summary sheets**, a **Developmental profile** and a **Glossary**. You can read more about each of these in the next section.

Read more about this in **Age norms and expectations**



Using the Journal

Recording progress using the Developmental steps

Within each of the 11 **Developmental steps** in the Journal you can record your child's progress in the five **areas of development** (communication, social-emotional development, cognition and play, motor and sensory development and self-help).

For each item listed for a **Step**, there are three different columns for you to complete:

- Emerging** Tick and date this column the first time you notice your child beginning to do something that demonstrates this skill or behaviour, even if it's only an attempt.
- Developing** Tick and date this second column when you notice your child using a skill or behaviour more often, as they become more skilful at it.
- Achieved** Tick and date this third column when you see your child doing something often, demonstrating the skill or behaviour independently and with confidence in a number of different situations – for example, in different rooms and different houses, with different toys, in interaction with different people etc.


You do not have to use all three columns, all of the time. For example, you may only notice a new speech and language or motor skill once it's already quite well established – i.e. it's 'developing' or 'achieved', rather than 'emerging'. **Only use all three columns if they're helpful to you as you track your child's progress over time.**

In the **communication** sections, you'll notice there are different boxes for noting down when your child is **signing** a word, and when they **speak** it. This is an important distinction for many children with Down syndrome. If you use signs with your child, they're likely to sign more words than they can say in the early days. It's important to record these differences as your child moves forward.

Notes or queries

There's a column on all the sheets for you to add comments, if you wish to do this. You might want to describe what your child does that demonstrates they're developing the particular behaviour or skill being recorded, for example, or you might want to note down any questions that you have for the professionals about what your child is doing. It could also be a place to record favourite toys, if they seem to encourage the behaviours you're seeing and trying to encourage.

Cognition and play

 Cognition	Emerging Behaviour is seen for the first time (date and child's age)	Developing Behaviour occurs sometimes (date and child's age)	Achieved Behaviour occurs often/usually (date and child's age)	Any notes or queries on how your child does this
Predicts/anticipates a familiar activity (e.g. gets excited upon seeing spoon, anticipates game from seeing a familiar toy, seems disturbed if familiar game changes)		✓ 11/05	✓ 12/05	Recognises bottle. In high chair kicks excitedly before food.
Very early imitation of adults (e.g. tries to move hands or object after watching adult)	✓ 11/05	✓	✓ March 06	
Repeats action to make sound again (e.g. shaking rattles, squeezing noise makers, kicking at baby gym)			✓ 09/05	
Persistently and deliberately reaches out for toys that interest him/her			✓ 10/05	
Recognises familiar environmental sounds (e.g. washing machine, microwave, footsteps). This is shown by quietening, consistent reactions, turning to look at source of sound etc.		✓ 12/05	✓	Shower and hairdryer
Looks around a room with interest			✓	
Uses feet to help in grasping objects			✓	



Expression
(using speech and/
or gesture)

Emerging
Behaviour is seen
for the first time
(date and child's age)

Developing
Behaviour occurs
sometimes
(date and child's age)

Achieved
Behaviour occurs
often/usually
(date and child's age)

Any notes or queries on how your child does this

Uses voice or **gesture** to:
 – attract attention (e.g. holding up objects, waving arms)
 – ask for things (e.g. reaching, opening and shutting hands)
 – refuse (e.g. pushing objects away, shaking head)

Uses voice, **gestures** or actions to join in with a familiar rhyme or game

Waves bye-bye through **imitation** (i.e. copies when others wave to him/her)

✓
11/05

✓ 05/06


✓
May 2006

03/06 ✓

Before ✓
Nov 2005

Clapping, copying actions,
bouncing and nodding

Motor and sensory Mother started keeping Journal November 2005

 <p>Large movements</p>	<p>Emerging Behaviour is seen for the first time (date and child's age)</p>	<p>Developing Behaviour occurs sometimes (date and child's age)</p>	<p>Achieved Behaviour occurs often/usually (date and child's age)</p>	<p>Any notes or queries on how your child does this</p>
<p>Walks with shorter steps and legs closer together – no longer needs to hold arms up for balance</p>			<p>✓ Before November</p>	
<p>Runs taking care – some difficulty with avoiding obstacles</p>		<p>Before November 2005</p>	<p>Before end 03/06</p>	<p>A toddler run - more of a fast walk</p>
<p>Starts to climb</p>			<p>Before Nov. 2005</p>	<p>Can walk up several steps, holding adult hand but not whole staircase yet</p>
<p>Walks upstairs holding hand of adult</p>		<p>✓ Nov 05</p>	<p>✓ 30/04/06</p>	<p>Not yet - March 2006</p>
<p>Steps backwards downstairs, holding on to each step</p>				<p>April 2006 can bump all way down</p>
<p>Bumps down a few steps on bottom</p>			<p>24/04/06</p>	<p>Beginning Nov. started to sit on bottom stair and play. Started to back into chair 24 November.</p>
<p>Gets onto child's chair without help backwards or sideways</p>		<p>✓</p>		<p>Usually sits or squats</p>
<p>Has a wide variety of different ways to sit to play</p>				
<p>Kneels upright on flat surface without support</p>			<p>Before Nov. 2005</p>	

Summary sheets

Each **Developmental step** has a **Summary sheet** that lists the key milestones in each **area of development**. You can complete these at the end of a **Step** as a summary of what has been happening and may want to copy them to share with others. Some people like to fill in the **Summary sheets** with a professional, because they support general discussion about how things are going and what comes next. **If you don't want to use the full set of material for a Step, the Summary sheets also provide a shorter alternative.**

The Developmental profile – getting an overview

At the beginning of the Journal, we have included a **Developmental profile** that helps you to see the pattern of your child's progress over time as they move through **Developmental steps**. It allows you to summarise what's going on, once you have filled out the more detailed tables and it gives you a 'bird's eye' view.

Once you have ticked 'achieved' for more than half of the items for a particular developmental area in a **Step**, enter the date in the corresponding box on the profile sheet. This will help you to record and celebrate progress over time and see at a glance the particular areas of strength and difficulty that your child has.

For example, a child may have moved on to **Step 6** in the **motor and sensory** and **social-emotional** areas, but still be at **Step 4** for **communication**. Within the **communication** area, a child may be up to **Step 8** for **attention, listening and understanding**, but still be at **Step 4** for **expression**.

Child's name: Gemma B

Date of birth: 4/11/04

Enter the date and your child's age in the corresponding box when you have filled out the more detailed material set out in the Journal and have ticked 'Achieved' for nearly all the items in a Step. Children are likely to be achieving new things in different Steps at any one time, so don't forget to check backwards and forwards as well.

Developmental profile

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Step 11
Communication											
Engagement and interaction with others	✓	✓									
Foundations of communication			✓								
Attention and listening				✓ 12/05	✓ 05/06						
Understanding											
Expression				✓		Sign	Sign	Sign	Sign	Sign	Sign
				05/06		Spoken	Spoken	Spoken	Spoken	Spoken	Spoken
Speech production											

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Step 11
Social-emotional											
Social-emotional understanding and expression			✓	✓ 10/05	✓ 05/06						
Attachment			✓	✓ 10/06	✓ 05/06						

Developmental profile

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Step 11
Cognition and play											
Sensory-motor development and play	✓	✓									
Cognition			✓ 10/05	✓ 12/05	✓ May 06						
Play			10/05	✓ 12/05	✓ May 06						

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Step 11
Motor and sensory											
Large movements			✓ 10/05	✓ 11/05	✓ Feb/March	✓ 04/06					
Fine movements and hand-eye coordination			✓ 10/05	✓ 12/05	✓ 03/06	05/06					
Vision			✓ 10/05	12/05	✓ 03/06						

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Step 11
Self-help											
Feeding	✓	✓	✓ 09/05	✓ 11/05	✓ 03/06						
Sleeping	✓	✓	09/05	✓ 11/05	12/05						
Washing				11/05							
Toileting											
Dressing											
Independence skills											



This information helps identify areas to target for further learning support and intervention, and particular strengths that can be used to support a child's development in other areas. Some of the professionals working with you may ask to photocopy the **Developmental profile**, as it provides a useful, at-a-glance summary of what is going on for people who are working with you and your child.

Worries or concerns

At times, your child may behave in ways that worry you. We have left a space at the end of each **Step** for you to note down these concerns so that you can discuss them with the professionals you meet. The Journal provides you with lots of opportunities to record all the new positive behaviours and skills your child achieves. However, children very often develop 'difficult behaviours' and it's important to discuss these as well – for example, how to set boundaries and help your child learn to behave in socially appropriate ways for children of their age. Sometimes children show 'different' rather than 'difficult' behaviours such as wanting to play in repetitive ways with toys or objects for longer than is usual for other children and it's important to discuss this as well.

This is an important space in the Journal, as we know that it helps children to move forward if help and support is given early – in other words, as soon as you notice behaviours that worry you.

Special achievements and things to celebrate

As has been explained, the Journal is organised in **areas of development** and **Steps** that reflect the way professionals describe child development. At the back of the Journal, you'll find another page where you can add details of any other special achievements and things you'd like to celebrate that are not covered in the tables. Use this section to identify important personal interests as well, if you'd like to do this. You can make notes about toys that your child enjoys playing with, activities which they particularly like or dislike, or their favourite foods. You could note the TV programmes they choose to watch, the places they enjoy going, or the people they look forward to seeing. The richer the description of

your child, the more chance you and the professionals you meet have to individualise early intervention activities to meet the needs of your child – in other words, to make what they do enjoyable and effective.

Glossary

Throughout the Developmental Journal there are words in blue, like [this](#). Blue text means that terms are explained and defined in the [glossary](#) at the end of the Journal. The idea is to give you access to the terminology or ‘jargon’ that you may hear being used by professionals as they talk about child development that may not be familiar to you.

A final comment

When you’re in the habit of using these records, there’s a danger you may focus on [Developmental steps](#) or [areas of development](#), rather than seeing your child as a whole. It’s important for everyone to keep reminding themselves about all the ways in which you and your child are succeeding and developing, and to celebrate success and progress whenever and however it happens.



Age norms and expectations

Babies and children with Down syndrome

Each child is an individual and it's important to remember this when you compare your child's development with any other child or group of children. Children with Down syndrome vary as much in ability, likes and dislikes, personality, and strengths as any other population. What's important is that your child continues to make progress in different areas at their own pace and in their own way – not how fast or slowly this happens.

For most children with Down syndrome, progress in all **areas of development** is affected in some way, with some aspects of development progressing faster than others – for example, children's social and emotional understanding and their ability to communicate non-verbally is often more advanced than their motor development or progress with talking.

You may also want to find out more about 'typical' patterns of development that emerge when children with Down syndrome are considered as a group. There is a 'developmental profile' with characteristic strengths and characteristic difficulties. You can read more about this in the Early Support Information for parents booklet on **Down syndrome**. You may already have been given this book with this Journal. If not, you can find out more about **Early Support** and about how to get hold of a copy at the back of this publication.

It's also important to remember that children who experience more health difficulties in the early months and years of life are likely to experience more developmental delay than their peers without health difficulties. However, once medical issues have been resolved and are under control, children typically go on to make progress in all areas.

Many children who seem to be making rather slow progress in the early months put on a spurt later. So please keep in mind that experts who have worked for many years with children with Down syndrome are not able to make reliable long-term predictions of what a child will achieve later on in life from their progress from birth to 5 years of age. Guidelines should not

and cannot therefore be used to try to predict the future development of any child with Down syndrome.

Because all children show wide variation in their patterns of development, the guidance on the rates of development that might be expected when a baby has Down syndrome and how this varies from 'typical' development given below must be treated with extreme caution. The tables offer a rough guide only. We have included the information only because some parents asked for it – **if it's not helpful for you, don't use it.**

Guidelines for typically developing children

The following table provides broad guidelines for 'typically developing' children considered as a group rather than for any specific child. For most children without Down syndrome, progress on items in the **Steps** described in this Journal overlap, and children achieve skills in different **Steps** at the same time. Each child moves forward at their own pace and in their own way. Some children make steady progress and some children move forward in spurts, with periods of consolidation in between.

Developmental Step	Approximate age/developmental level for typical developing children
Step 1	0 – 3 months
Step 2	2 – 5 months
Step 3	4 – 7 months
Step 4	6 – 10 months
Step 5	9 – 13 months
Step 6	12 – 16 months
Step 7	15 – 19 months
Step 8	18 – 22 months
Step 9	21 – 25 months
Step 10	24 – 31 months
Step 11	30 – 36 months

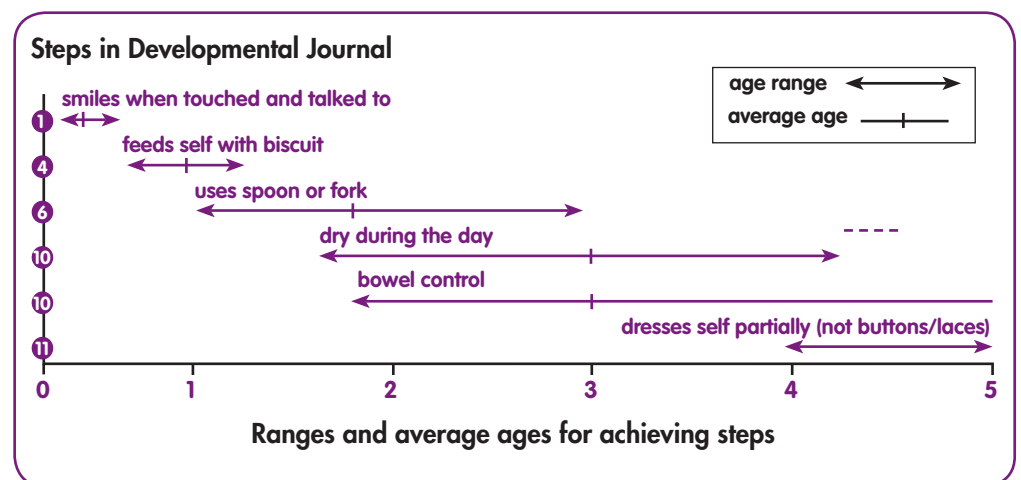


Guidelines for children with Down syndrome

The information about children with Down syndrome presented below is the best that can be provided at present. The figures are based on information in published research studies, but these studies are based on relatively small numbers of children and more research is needed, to provide more reliable norms. The Developmental Journal, when it is in use around the country, may help us to collect some of this information in coming years.

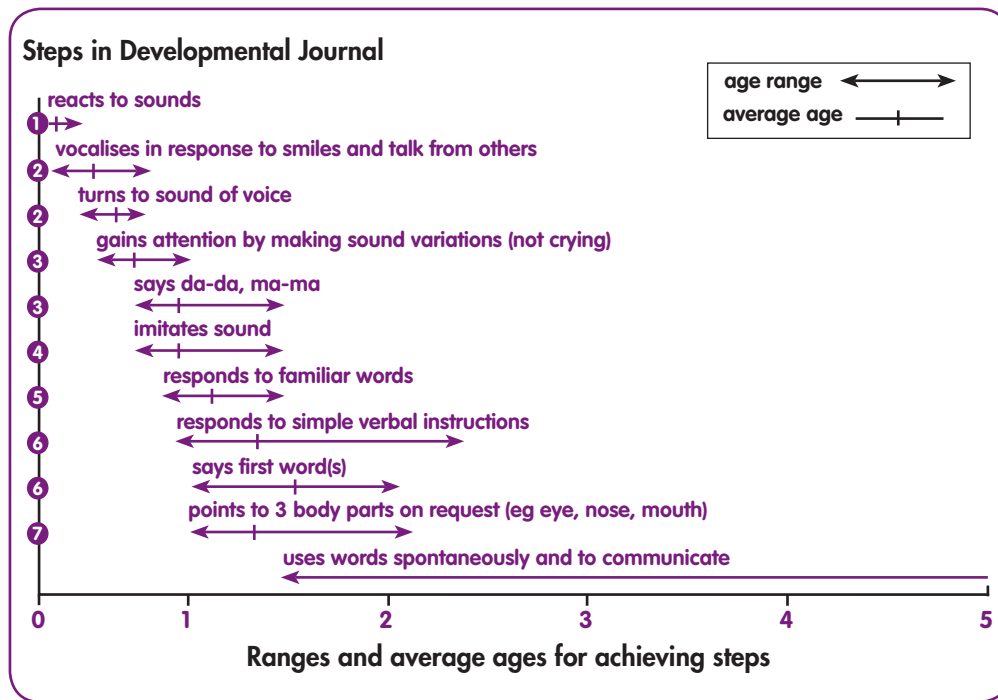
The following charts are based on the best available data¹ for some key milestones identified in the Developmental Journal in each **area of development**. Each chart shows the range of ages at which a child with Down syndrome may achieve each milestone, as well as the average age that the data indicates they might do so. Each chart also shows the **Step** in the Developmental Journal for that milestone. Further detail about expectations for each area of development can be found in the *Down Syndrome Issues and Information* series of publications¹.

Social and self-help skills

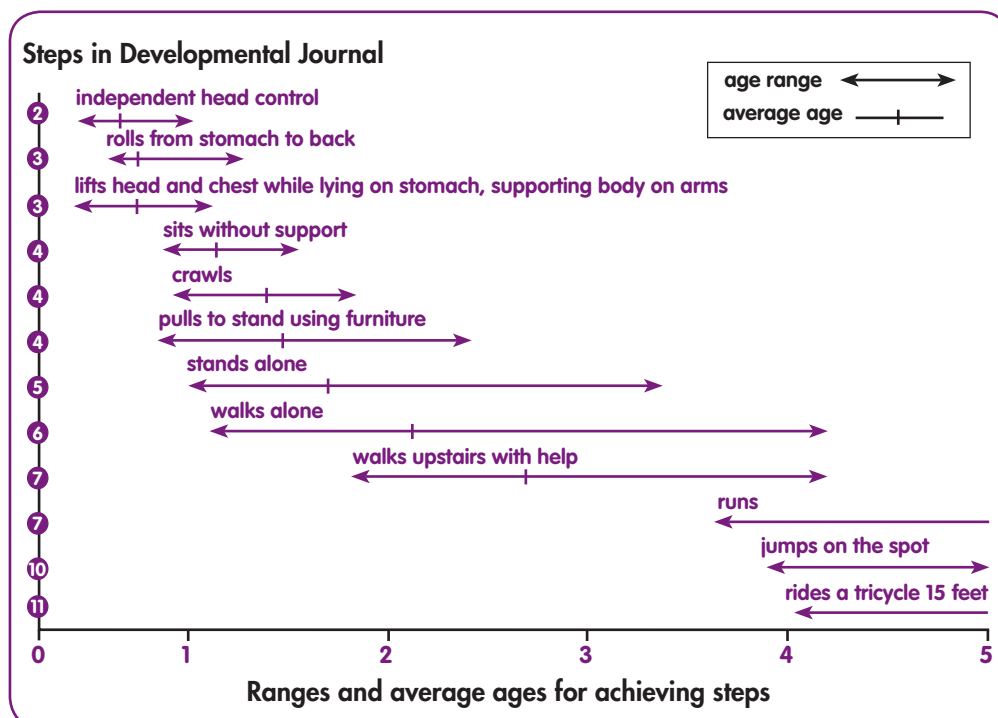


¹ *Down Syndrome Issues and Information* (2000 – 2006) contains up-to-date reviews of the information available on the development of children with Down syndrome and guidance on evidence based practice. Available in print and on-line – see www.downsed.org

Communication

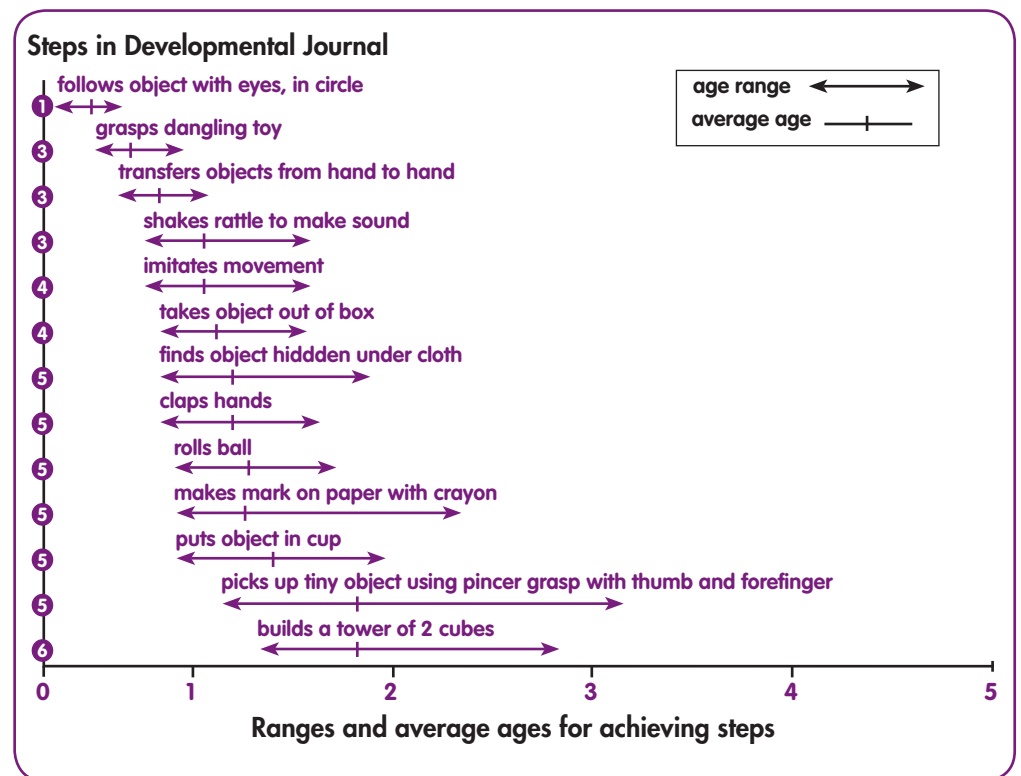


Gross motor skills





Fine motor and cognitive/adaptive skills



These milestones have been drawn from the following sources:

Down's syndrome: an introduction for parents
 Cunningham
 London: Souvenir Press (1987)

Helping your handicapped baby
 Cunningham and Sloper
 London: Souvenir Press (1978)

Language development in children with special needs
 Johansson
 London: Jessica Kingsley Press (1994)

Teaching the infant with Down syndrome

Hanson

Austin, Texas (1987)

Gross motor skills in children with Down syndrome

Winders

Bethesda, MD, Woodbine House (1997)

Other resources for families and professionals working with children with Down syndrome

A wide range of materials are available to parents from the following organisations:

- The Down's Syndrome Association – www.downs-syndrome.org.uk
- The Down Syndrome Educational Trust – www.downsed.org
- Down's Syndrome Medical Interest Group (DSMIG) – www.dsmig.org.uk
- I Can – www.ican.org.uk
- Makaton Vocabulary Development Project – www.makaton.org
- The Signalong Group – www.signalong.org.uk

The Early Support Information for Parents Booklet on *Down syndrome* lists further useful contacts and organisations.



How the material was developed

The material was developed at the Down Syndrome Educational Trust in Portsmouth, with the support of an advisory group.

The development team comprised:

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John Clibbens

Gaye Powell

Professor Sue Buckley

Over 70 families with children under 5 attending the Early Development Groups in Portsmouth were involved in commenting on the materials and piloting their use over a two-year period. In 2006, events were held in Plymouth, Bristol, Sheffield, Nottingham and Bradford, involving a further 110 families with young children and professionals. The final consultation events were facilitated by members of the development team and by the Down's Syndrome Association.

Advisory group

Chair

Prof Sue Buckley OBE Director for Research and Training, The Down Syndrome Educational Trust and Emeritus Professor of Developmental Disability, Department of Psychology, University of Portsmouth

Psychologists

John Oates Senior Lecturer in Developmental Psychology, Centre for Childhood, Development and Learning, Open University

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Speech and Language Therapists

Nicola Grove Senior Lecturer, Dept of Language and Communication Science, City University

Gaye Powell Head of Speech and Language Therapy Services, Plymouth, representing the Royal College of Speech and Language

Therapists

Leela Baksi Symbol UK (specialising in services to children with Down syndrome). Symbol UK is advisor to the Down's Syndrome Association



Karen Imrie	Specialist Speech and Language Therapist and Advisor to Down's Syndrome Scotland
Katie Hillier	The Down Syndrome Educational Trust
Teachers/Portage	
Annie McGee	Head of Plymouth Early Years Inclusion Service
Jonty Rix	The Centre for Curriculum and Teaching Studies, Open University and member of the Portage National Committee
Julie Hughes	The Down Syndrome Educational Trust
Sue Lewis	Director for Educational Development and Inclusion, Mary Hare, Newbury and lead for the development of the Early Support Monitoring Protocol for Deaf Babies and Children in 2003/4
Medicine and professions allied to medicine	
Sarah Crombie	Association of Paediatric Chartered Physiotherapists
Dr Liz Marder	Consultant Community Paediatrician, Nottingham and Chair of the Down's Syndrome Medical Interest Group (DSMIG)
Mary Joyce	Clinical Specialist, Paediatric Occupational Therapist, Southend University Hospital NHS Foundation Trust, representing NAPOT
Lorraine Grieve	Specialist Health Visitor, Child Development Centre, Portsmouth and representative from national SIG
Voluntary organisations	
Carol Boys	Chief Executive, Down's Syndrome Association
Julian Hallett	Development Director, Down's Syndrome Association
Cliff Lake	Chair, Down's Heart Group
Leslie Campbell	MENCAP

Down Syndrome Educational Trust

The Down Syndrome Educational Trust (DownsEd) is a leading international charity focused on the education and development of individuals with Down syndrome. Since 1979, researchers at the Trust have undertaken pioneering research into the development and education of individuals with Down syndrome. This research has helped identify a range of practical strategies to promote the development of children with Down syndrome. All of the Trust's services and publications draw on the evidence of this research as well as extensive practical experience.

The Trust:

- publishes a broad range of information and guidance on Down syndrome – in print (including the *Down Syndrome Issues and Information* series of books) and online.
- runs training workshops and lectures for parents and professionals across the UK and throughout the world.
- offers individual advice and support through a free AdviceLine service and consultancy services for families.
- supports inclusion in education by providing expert training, support and consultancy for teaching staff and education authorities.
- provides early intervention services for babies and pre-school children to help parents give their children the best start in life.
- operates a specialist mail order service selling books and teaching resources for children with Down syndrome.

The Down Syndrome Educational Trust

The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire PO5 1NA

Tel: 023 9285 5330

Fax: 023 9285 5320

Email: enquiries@downsed.org

Web: www.downsed.org and www.down-syndrome.info

**the down syndrome
educational trust**

<http://www.downsed.org/>



Early Support

Early Support is the central government mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across England. It is developing at a time of significant change, as part of the restructuring of children's services in response to *Every Child Matters* and alongside new integrated assessment, information and inspection frameworks for children's services.

Early Support builds on good practice. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children.

To find out more about the Early Support programme visit www.earlysupport.org.uk

If you would like a copy of the other Early Support publication mentioned in this booklet, which is available free of charge, please ring 0845 602 2260 and ask for the following:

Information for parents booklet on *Down syndrome* ESPP13

The booklet provides general information for families with young children with Down syndrome.

Copies of this publication can be obtained from:
DfES Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ
Tel: 0845 602 2260
Fax: 0845 603 3360
Textphone: 0845 605 5560
Email: dfes@prolog.uk.com

Please quote ref: ES49

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www.earlysupport.org.uk

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