contact a family
for families with disabled children



Developmental delay

Information for families

UK

Incorporating The Lady Hoare Trust

Introduction

This guide is for parents and carers who think their child is not developing as they ought to be, or who have been told that their child has developmental delay or global developmental delay. It contains information on:

- what developmental delay is
- progress in the early years
- why a child might be slower in development
- top tips.

About this series

It might take some time from when you first become concerned about your child's development to being given a diagnosis. The 'About Diagnosis' series by Contact a Family deals with topics that may be useful to parents going through this process. Each guide contains information and signposts to further sources of support for parents. Other guides currently available in our 'About Diagnosis' series are:

- *Living with a rare condition*
- *Living without a diagnosis.*

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Colour key to reading this guide

Words in blue in this guide are organisations listed in 'Sources of information' from page 12. Words in brown in this guide are explained in the 'Glossary' on page 12.

What is developmental delay?

Babies and children usually learn important skills as they develop, such as making eye contact, becoming attached to certain people, babbling (making basic speech sounds), saying their first words, handling toys, rolling over and taking their first steps.

These skills are known as 'developmental milestones' and usually happen at fairly predictable ages.

A child with developmental delay is much slower in reaching one or more of these milestones than expected.

This delay can occur for a variety of reasons and some children eventually catch up. Development delay sometimes occurs because the child is born with a medical condition which restricts their development.

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Key messages for parents

- Children develop in their own way and the pace at which they develop will vary from child to child.
- If you are worried about your child's progress you should talk to your health visitor or GP.
- Your health visitor or GP might suggest activities you can do with your child to support their development.
- Your child might be referred for a developmental assessment.
- Support can be put in place to help your child develop skills, regardless of whether they have been diagnosed with a medical condition.
- The best way to help your child make progress is to get advice and support.

Children's progress in the early years

Most children develop more abilities during the first five years of their lives than at any other time. Their first achievements can be encouraged by how we behave with them – for example, giving them love and affection, singing, talking, listening and playing with them. The main areas of learning and development are:

Personal, social and emotional – such as copying facial expressions, responding



to what parents say and becoming a conversational partner, forming close attachments, playing with other people, showing affection and concern for others, learning to wait or take turns, feeling confident in themselves.

Communication – such as smiling, listening, responding to words, pointing to objects, talking, reading and writing, and expressing needs, thoughts and feelings.

Physical – such as holding and handling objects, sitting up, crawling, walking, using the toilet, dressing themselves, and becoming agile and exploratory.

Thinking – learning about the world, developing understanding, solving problems and being creative.

Important milestones

The tables in the fold out poster in the middle of the printed version of this guide list the ages by which most children will have gained certain skills in four key areas of development:

- **personal, social and emotional**
- **communication**
- **physical**
- **thinking.**

Some children are quicker in reaching these milestones than others, or quicker at developing in some areas than others. For example, a child might walk at an early age but be slower than other children in learning to talk.

If your child has not reached these milestones by these ages it is advisable to talk about it with your health visitor or GP. More detailed information on this can be found in the 'Birth to Five' section of the NHS Choices website at www.nhs.uk/Tools/Pages/birthtofive.aspx

Why might a child be slow in development?

A child's development can be slower than others for various reasons, including if they are born prematurely or become ill. If a child becomes severely ill they may even appear to regress and no longer be able to do things they could before the onset of the illness. For most children, once they recover, their development will speed up and they will catch up.

Family events such as the arrival of a new baby in a family can also cause a child to slow down their progress for a short while. If a child's progress slows for a while, and there seems to be a reason for this, such as one of the above events, this is not necessarily a cause for concern. But if the delay is persistent, or happens for no obvious reason, it is important that you seek advice so that any necessary help can be given as soon as possible.

Every parent is given a Personal Child Health Record when their baby is born where they can record the dates when their child reaches certain milestones. It is really useful to do this as it helps later on to share concerns about how their child is developing.

Any accident or illness that affects the brain can also impact on a child's development.

Some children will be slower in their progress because they are born with a medical condition which restricts their development. This condition might be diagnosed shortly after their birth. However, a child being slow in their development can sometimes be the first sign that the child has an underlying medical condition.

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What to do if you are concerned

If you are worried about your child's progress you should talk to your health visitor or GP.

It can be helpful to have your Personal Child Health Record with you. Your health visitor or GP might suggest activities you can do with your child to support their development. This might be all that is needed.

However, if after four to six weeks, or after having tried the activities, you are still worried, go back and tell your health visitor or GP.

It is well known that parents are often the first to realise that their child is not developing in an expected way or at the same pace of other children of the same age. Your health visitor or GP might discuss referring your child to be assessed for developmental delay.

Types of delay

Delay might be specific to one particular area of development. For example, children with muscular dystrophy will have specific delays in their physical skills. Children on the autistic spectrum will be slow in developing personal social and communication skills.

A child may be described as having global developmental delay (GDD) if they are slow in reaching two or more milestones in all areas of development.

Once it is established that the child may never catch up with their development, health professionals might use the term developmental impairment, or disordered development instead of developmental delay.

It is important that different types of delay are identified as early as possible so support can begin, tailored to your child's specific needs.

Early Years Foundation Stage Framework (EYFS)

In England all children's centres, nurseries and preschools are required to have staff trained to assess and encourage a child's development through the Early Years Foundation Stage. Most childminders are also registered to deliver the Early Years Foundation Stage.

Staff at these centres can assess a child's progress in development and suggest fun activities for parents to do with their child to support their progress.

Parents should receive an assessment of their child's progress at the age of two and five from early years settings. You can read more at www.foundationyears.org.uk/parents

Early Support Developmental Journal

The Developmental Journal for Children and Young People with Multiple Needs helps you record and celebrate your child's learning and development in the four areas of learning and development:

- Personal, social and emotional
- Communication
- Physical
- Thinking.

Lots of practical ideas are given on how progress might be encouraged in different areas of development, in different contexts and with different materials.

See www.ncb.org.uk/early-support resources

It is generally the case that the earlier support is put in place, the better chance of improvement for a child's development.

Assessments – what to expect

If your child is referred for further assessment they could be seen by a paediatrician, who is a doctor specialising in children's health and wellbeing. The paediatrician might order tests for specific conditions that could be causing the delay in their development. You might also see a:

Physiotherapist – if your child requires help to sit up, crawl or walk.

Speech and language therapist – if your child requires help to develop speech, language and communication or has difficulty chewing food or swallowing.

Occupational therapist – if your child needs help with developing their physical skills or finds it difficult to manage everyday tasks by themselves, for example in feeding, dressing or playing.

Educational psychologist – if your child needs help with learning and with benefiting from a learning setting.

"At first I was cross because the doctor did not know much about my daughter's medical condition. It was much later that I discovered she was the first child the doctor had ever seen with that condition." Parent

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Clinical psychologist – if your child might have emotional or behavioural difficulties.

The professionals are likely to ask questions about how your child has developed since birth and may want to spend time observing and possibly giving them one or more developmental assessments. Professionals are likely to be interested in how your child moves, how many words your child understands and how they play with toys and other people. If you have been recording your child's progress in their Personal Child Health record, they will find this information useful.

The specialists might suggest ways to help your child make more progress. For example, activities to improve movement and coordination or ways to help your child develop their speech and communication. They might ask you to keep a record of your child's development, to note their achievements and areas for improvement.

If the specialist says there is nothing to worry about but you are still concerned, do go back to them or talk to your GP.

Why it can take time to make a diagnosis

Specialists will consider all the different areas of concern for your child and think about the most likely reasons for their difficulties. They might carry out tests to rule out possible causes or to confirm what the reasons are. They may even find a name or 'diagnosis' for the condition. However, different conditions can cause similar symptoms and it is not always possible to test for all of these.

> "I felt that getting a name for our daughter's condition would help us when explaining to others what was wrong, but in the end it didn't really matter. All the professionals involved needed to know was what the immediate difficulties were, so the right care could be arranged." Parent

It might be necessary to wait to see if your child makes progress in their development, or for other symptoms to appear that will help in making a diagnosis.

If a child has a rare condition it can be even more difficult for doctors to identify the reasons, as less is known about the condition and the doctor might never have seen someone with that condition before.

Advances in science and genetic testing means new conditions are being identified all the time. It is not possible

for doctors to know about all of these conditions, but this should not prevent them from being able to treat your child's symptoms.

Children can sometimes wait for years for a diagnosis and some never get a diagnosis, but support is still available for them even without a diagnosis. Some parents can find this a worrying time. Not having a diagnosis for a child's condition can seem worse than knowing and parents are often bewildered by what could be the cause.

Not all parents, however, will react in this way. Sometimes parents prefer not to have a diagnosis as this helps them focus on the issues that are happening rather than compare their child with others with the same condition. Even if your child has been diagnosed with a condition, it can still be difficult to know how this will affect them as the same condition can affect children in different ways.

Support with or without diagnosis

Your child is entitled to support and help, regardless of whether or not they have received a diagnosis. The support they receive should be based on their additional needs and not the name of their condition.

Developmental delay should be addressed as early as possible to help your child make progress. A delay in one area can affect other areas of a child's development. For example, a child who has difficulties in communication and is not helped, may find it more difficult to learn when they go to school.



Working with professionals to assist and encourage your child's development and learning is the best way you can support your child and help them get the best possible outcome.

Who can help?

Speech and language therapists, physiotherapists, occupational therapists and educational psychologists are some of the people who can help support a child's development. They can also advise the other people involved in caring for your child, for example in children's centres, nurseries and schools.

(continues on page 11)

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www.cafamily.org.uk

Top tips from parents

- Parents are often the first to notice their child has a problem. If you are concerned about your child's development discuss it with your GP or health visitor.
- Use your Personal Child Health Record to record your child's achievements and at what age they occurred. This can be a useful aid when discussing your concerns with health professionals.
- Before going to appointments, think about what you want to say and any questions you want to ask. It can help to write these down and take along with you.
- If you don't understand what you are being told, say so and ask them to explain it again. Don't be afraid to ask questions however silly or insignificant you think they may seem.
- Take someone with you who can take notes while you talk.
- Listen to the advice offered and ask to have another appointment if you feel you need time to think about what has been said.
- If you feel that your child needs an assessment or to be seen by a specialist, don't be afraid to ask.
- You should not have to wait for a diagnosis before getting support for your child's development. Talk to your GP, health visitor, children's centre and, if your child is in nursery or school, talk to the Special Education Needs Coordinator about what help can be provided.
- Concentrate on what you can do to help and support your child now – rather than worry about difficulties they might or might not face in the future.
- Don't forget your friends and your family too! Include them in discussions right from the start so they can learn and understand with you.
- Spend time having fun with your child and enjoy what they CAN do.
- You might find sharing your thoughts and ideas, hopes and fears with other parents and carers helpful.

Some questions you might want to ask

- Can my child have an assessment of their development by a speech and language therapist, or educational psychologist, or physiotherapist, or occupational therapist?
- Are there tests that could be carried out check if my child has a genetic condition which is causing these problems?
- How frequently are you going to review my child's development? What support do you think my child needs in nursery or school - how do I get this put in place?

If your child's progress is very delayed and they are not in a preschool setting, you might be offered a home visiting service (in England the portage scheme provides this) where a trained Early Years professional visits your house regularly to help and advise you in supporting your child's development through activities and play. This type of support can be invaluable in helping you to understand how to help your child make progress. Other professionals might be involved as well. You can read about them in our parent guide *Concerned about your child*. Call our freephone helpline on 0808 808 3555 for a free copy.

It can be harder for children with a developmental delay to master new skills such as toilet training or dressing and feeding themselves. There may also be some issues around sleep and behaviour. We have guides on *Helping your child's Sleep, Feeding and eating, Potty/toilet training,* and *Understanding your child's behaviour*. Call our freephone helpline on 0808 808 3555 for a free copy.

Early Support provides a range of information and other forms of support for parents which you might also find helpful. – see www.ncb.org.uk/early-support

You may find it useful to get tips to help with these sorts of issues early on and parent training or workshops might be helpful in suggesting strategies.



Contact with other families

Parents often report feeling lonely and isolated, and that other people do not understand what they are going through. Families often find it helpful to get in contact with others who are going through, or have been through, similar experiences. Parents frequently say that other parents have been their best source of information and support.

Contact a Family can help you make contact with other parents of disabled children. You can call our freephone Call our freephone helpline on 0808 808 3555 for details of support groups in your area, as well as national support groups. You can also visit our website www.makingcontact.org for families with disabled children, can find and contact others affected by similar disabilities or contact other disabled people from the same area.

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www.cafamily.org.uk

Sources of information

Contact a Family

Contact a Family can provide support to families even if their child does not have a diagnosis. We offer information, advice, support to any parent or carer of a child with additional support needs through our freephone helpline. Our parent advisers will help you with any issue around raising a disabled child, whatever your concern or question.

Early Support

Web: www.ncb.org.uk/early-support
The Early Years Developmental Journal is designed for families, practitioners and others to use as a way of recording, celebrating and supporting children's progress. Early support also have parent guides on issues such as sleep and behaviour.

The Communication trust

www.thecommunicationtrust.org.uk
The Communication Trust's 'Small Talk' project provides information about what helps children aged 0 to 5 learn to talk and listen, whether they are on the right track, and what parents can do if they have concerns about their child. You can also find *Other Ways of Speaking, Supporting children and young people who have no speech or whose speech is difficult to understand* on the website



Glossary

Autistic spectrum
Also known as autistic spectrum disorder (ASD). Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. Having autism also affects how someone makes sense of the world around them. Autism is a spectrum condition, which means that while all people with autism share certain difficulties, the condition affects them in different ways.

Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support.

Asperger syndrome
Asperger syndrome is a form of autism. People with Asperger syndrome are often of average, or above average, intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language and social skills.

Clinical psychologist
Clinical psychologists work with parents, carers and children to address behaviour problems. They use knowledge about how children develop, how behaviour problems occur and how to change behaviour problems. They can also play a part in assessing children's skills and helping them develop new skills.

Developmental assessment
Developmental assessment is the process of mapping how a child is developing, compared with what is considered usual for children of a similar age.

Developmental impairment, or disordered development
Term used when a child has a developmental issue which will affect them all their life.

Developmental milestones
Babies and children usually learn important skills, such as making eye contact, becoming attached to certain people, babbling (making basic speech sounds), saying their first words, handling toys, rolling over and taking their first steps at fairly predictable ages. These skills are known as developmental milestones.

Educational psychologist
Educational psychologists help children or young people who are experiencing problems within educational settings with the aim of enhancing their learning. Challenges may include social or emotional problems or learning difficulties.

"There was a mum who lived nearby whose daughter had Down's syndrome. I got more information and support from her about getting local services for my child than anyone else." Parent of a child with Pallister-Killian syndrome

General Practitioner (GP)
This is your family doctor. They will be the first person to ask for medical help and advice. They can ask for your child to be seen by another specialist.

Local parent support groups
Many areas in the UK have a local parent support group, where families of children with all kinds of additional needs come together for mutual support and contact.

Global developmental delay (GDD)
A child may be described as having global developmental delay (GDD) if they are slow in reaching two or more milestones in all areas of development.

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Occupational therapist (OT)
OTs help children and young people who have difficulties in carrying out everyday tasks; for example, eating, dressing or playing.

Paediatrician
A paediatrician is a doctor who specialises in looking after babies, children and young people. A paediatrician can coordinate and liaise with other agencies involved in the management, care and education of the child and family.

Physiotherapist
A physiotherapist helps in the management and development of movement skills. Physiotherapy may include exercises to strengthen weak muscles and games to improve coordination and motor skills.

Speech and language therapist
Speech and language therapy helps children learn to communicate, either through speech or other methods. Speech and language therapists can also help if there are problems with eating, drinking and swallowing.



Written by Sheila Davies, September 2013.

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Social networking
Contact a Family is on Facebook and Twitter. Join us at:

Facebook
www.facebook.com/contactafamily

Twitter
www.twitter.com/contactafamily

Videos
You can watch videos on our YouTube channel at:
www.youtube.com/cafamily

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Getting in contact with us

Free helpline for parents and families
0808 808 3555
Open Monday to Friday,
9.30am–5pm
Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:
209–211 City Road, London EC1V 1JN
Tel **020 7608 8700**
Fax **020 7608 8701**
Email **info@cafamily.org.uk**
Web **www.cafamily.org.uk**

Language Line services

Other guides available

This guide is one of in a series produced for parents and groups concerned with the care of disabled children. Other guides include:

- *Understanding your child's behaviour (UK)*
- *Relationships and caring for a disabled child (UK)*
- *A guide to claiming Disability Living Allowance for children (UK)*
- *Additional support for learning – Scotland*
- *Special educational needs.*

Contact a Family publications can be downloaded from our website at www.cafamily.org.uk
Parents can call our freephone helpline on 0808 808 3555 and ask for a copy of any of our guides.

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