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# A parents' guide to the investigation of intellectual disability / developmental delay in children



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How to reference this guide

**A parents' guide to the investigation of intellectual disability /  
developmental delay in children  
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# Introduction

When there are concerns about your child's development, it can be hard to know whether they are just developing at a slower rate than others and will catch up, or whether they are going to need some extra help. Sometimes this needs to be investigated. You have been given this leaflet to explain how developmental delay can be assessed and what help is available.

## What is developmental delay?

Developmental delay is a broad term used when a young child does not progress as expected. For example, they may be late in talking or slow to learn to walk. In some children it is suspected soon after birth because of feeding difficulties or unusual muscle tone. In other children, developmental delay is only suspected much later when learning or behavioural difficulties surface at school. In older children, terms such as learning difficulty, learning or intellectual disability may be used, although not all children labelled with developmental delay will go on to have a diagnosis of intellectual disability.

*"He was very floppy as a baby. He wasn't able to support his head at all and people used to comment on how hard it was to hold him. It turned out this was poor muscle tone and was the first sign that something wasn't quite right."*

## What causes developmental delay?

There are many different causes for developmental delay. It is a common condition affecting 1-3% of the population. The delay may be caused by a child's genetic makeup (e.g. Down's syndrome), by problems during pregnancy or around the time of delivery, or by problems in early infancy (e.g. meningitis). It is not always possible to find a cause but one can be found in about half of cases.

## Why can it be useful to find a cause?

There are a number of benefits for you and your child to finding out what might be causing the developmental delay. These include:

- Helping you and your child's health professionals to understand the condition and how it may affect your child in the future
- Helping you to find the best ways to care for your child
- Helping you, as parents, make contact with a support group and other families
- Addressing concerns you might have about events that happened before your child was born
- Helping you find out whether any future children you or your family have could also have the condition.

*"While not knowing in the early days allowed us a period of normality with our baby, later we reached a point where we simply needed to know more about why he was not developing and what the future would bring. It was a very unsettling time because I was using every waking hour of the day to try and "reach" my son. I was clutching at straws"*



## Assessment of developmental delay

A paediatrician (a doctor specialising in children) usually does the initial assessment of developmental delay. They will ask questions about your child's medical history, examine your child, and assess your child's developmental progress against typical developmental milestones. It can be useful to keep your red book up to date and bring it along to assessments as this is a record of when your child achieves various milestones.

A number of other professionals may be involved in this assessment and you may find you are having to attend large numbers of appointments. Your child may be offered tests of hearing and vision. Additional referrals or tests might also be offered, such as a referral to a neurologist (a doctor who deals with the brain and nervous system) or a clinical geneticist (a doctor who deals with a person's genetic makeup) to try to determine the cause of your child's developmental delay.

## Genetic tests

These are tests looking for a genetic cause for the developmental delay – that is, whether there is something in your child's genetic make up that can explain their difficulties. Testing can help identify whether the cause of your child's difficulties is inherited from a parent or whether they have occurred spontaneously (a one-off occurrence in that particular child).

Tests usually involve taking blood or urine samples from your child. Samples may also be taken from parents to find out whether either parent is a carrier of the genetic disorder. X-rays or brain scans may sometimes be helpful, and your paediatrician can help you decide if this is something you wish to consider.

### When will we get the results?

It varies considerably. Although some test results may come back within a few days, others are likely to take a few weeks. For more complicated or rare conditions, the results can take several months. You can ask your paediatrician or clinical geneticist for an estimate of how long it will take to get the results back.

Waiting for results can be a stressful time for families and you might find it helpful to talk to your health visitor or school nurse during this period, or to explore some of the local parent support groups.

### What if a diagnosis is made?

The paediatrician or clinical geneticist will explain what the diagnosis means for you and your child; for example what the common features of the condition are, whether there is any treatment for the condition and whether the condition can be passed from one generation to the next.

Even though most parents would like to know the cause of their child's developmental delay, the news may still come as a huge shock. Parents can find it difficult to concentrate on all the information given to them about their child's diagnosis and it may be helpful to bring someone else along to the appointment with you. You may also want to consider whether it would be best for your child not to be present at the appointment when the results are given.

Receiving a specific diagnosis can be difficult and reactions vary widely but commonly include relief, shock, numbness, grief and guilt. It may be helpful to discuss these feelings with your paediatrician or GP, or to access support through parental support groups.

Although a diagnosis can come as a shock, most families believe it was worth investigating and report a sense of 'being able to move on'.

*"In retrospect I think that I really wanted to know if there are other children out there with the same condition or other families who might also have been through it...I just didn't want to feel alone anymore..."*

### What if there is no diagnosis?

In spite of investigations, approximately half of children with developmental delay will not receive a specific name for their condition. In those cases where a name is not given, it is common for parents to have a mixture of feelings:

- Relief that their child does not have the condition that was being tested for
- Disappointment/frustration that a cause has not been found
- Isolation that they don't know anyone else whose child has the same condition

Even if there is no diagnosis, the paediatrician or clinical geneticist may be able to say what the most likely cause of your child's developmental delay is; for example an event during pregnancy or a genetic condition. As medical knowledge improves, you may be given the chance to test your child again and you may be advised to request further testing in 3-5 years time.

It is important to remember that, with or without a diagnosis, services for your child will not be affected. It is also important to remember that many families will be in the same position and that support and advice is available with or without a diagnosis.



### What services will be available to my child?

Your child may benefit from a number of services, each equipped to deal with different aspects of a child's development. Therapy services such as physiotherapy (for the management and development of movement skills), speech and language therapy (for help with speech or alternative forms of communication, or difficulties with swallowing) or occupational therapy (sensory needs and advice on specialised equipment) may all be of use to your child. Other services such as Portage or music therapy may also be available and you should ask your paediatrician about access to these.

SENCOs (Special Educational Needs Co-ordinators) will play a key role in helping you plan for your child when they reach pre-school or school age and provide advice on accessing an EHC plan (Education, health and care plan - formerly known as a Statement of Special Educational Need). This will help ensure that they receive the correct support within school as well as looking at their wider areas of need.

### And finally...

Remember that developmental delay does not stop a child from having a full and rewarding life and this assessment process is designed to ensure you are offered all the advice and information available to support you and your family.



# Support groups and organisations

If you do not understand something in this leaflet, contact your health visitor (for preschool children) and/or school nurse (for older children) who may also be able to put you in contact with a relevant support group.

## Pinpoint

[www.pinpoint-cambs.org.uk](http://www.pinpoint-cambs.org.uk)

Information for parents by parents – runs regular support and wellbeing groups for parents and provides local information on services.

0148 049 9043

[information@pinpoint-cambs.org.uk](mailto:information@pinpoint-cambs.org.uk)

## Families Information Service

[www.cambridgeshire.gov.uk/families](http://www.cambridgeshire.gov.uk/families)

Online information for all families with children 0-19 and up to age 25 with special educational needs or disabilities (SEND).

0345 0454 014

[fis@cambridgeshire.gov.uk](mailto:fis@cambridgeshire.gov.uk)

## Parent Partnership Service (PPS)

[www.parentpartnership.org.uk](http://www.parentpartnership.org.uk)

Confidential and impartial advice and support on SEND matters, eligibility and entitlement.

01223 699 214

[pps@cambridgeshire.gov.uk](mailto:pps@cambridgeshire.gov.uk)

## Contact a Family

[www.cafamily.org.uk](http://www.cafamily.org.uk)

A UK wide charity providing advice, information and support to parents of all disabled children – no matter what their health condition.

[www.makingcontact.org](http://www.makingcontact.org)

A linking website linking parents of children with the same disability or condition on a local or national basis.

0808 8083 555 (The helpline has interpreters for over 170 different languages ).

[helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

## Scope

[www.scope.org.uk](http://www.scope.org.uk)

A charity that exists to make this country a place where disabled people have the same opportunities as everyone else.

Helpline 0808 800 3333

[helpline@scope.org.uk](mailto:helpline@scope.org.uk)

## Carers Trust Cambridge

[www.carerstrustcambridgeshire.org](http://www.carerstrustcambridgeshire.org)

Expert carer support and care services across the county.

0148 049 9090

[care@carerstrustcambridgeshire.org](mailto:care@carerstrustcambridgeshire.org)

## Unique

[www.rarechromo.co.uk](http://www.rarechromo.co.uk)

The rare chromosome disorder support group exists to inform, support and alleviate the isolation of anyone affected by a rare chromosome disorder and raise public awareness.

0188 372 3356

[info@rarechromo.org](mailto:info@rarechromo.org)

## SWAN UK

Syndromes Without a Name

[www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

## Global Developmental Delay

[www.globaldevelopmentaldelay.co.uk](http://www.globaldevelopmentaldelay.co.uk)

Page to help raise awareness of GDD and give links for better support.

[globaldevelopmentaldelayuk@gmail.com](mailto:globaldevelopmentaldelayuk@gmail.com)

Facebook - search for 'Facebook gdd group'

## Mencap

[www.mencap.org.uk](http://www.mencap.org.uk)

Work in partnership with people with a learning disability and all our services support people to live life as they choose.

0808 808 1111

[help@mencap.org.uk](mailto:help@mencap.org.uk)

## Afasic

[www.afasic.org.uk](http://www.afasic.org.uk)

Supports parents and represents children and young people with speech, language and communication needs (SLCN).

Parents' Helpline 0845 355 5577

## Cerebra

[www.cerebra.org.uk](http://www.cerebra.org.uk)

A charity set up to help improve the lives of children with brain related conditions through research, education and directly supporting the children and their carers.

Helpline 0800 328 1159

[enquiries@cerebra.org.uk](mailto:enquiries@cerebra.org.uk)

