

Early Support

Helping every child succeed

Information for parents

When your child has no diagnosis



About this publication

This booklet is for parents with young children with additional support needs where no diagnosis has been made and there is no obvious cause for the difficulties that a child experiences.

It was developed by the **Early Support** programme in partnership with **Contact a Family**, in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content and this text reflects what parents who have 'been there before' say they would have liked to have known in the early days of finding out about their child's situation.

This edition of the publication was updated by **Contact a Family**.

To find out more about **Early Support** and to obtain copies of other Early Support materials, visit www.dcsf.gov.uk/everychildmatters/earllysupport

Where a word or phrase appears in **colour**, like this, it means either that it is a technical term that is explained in the text around it.

If the name of an organisation appears in **colour**, it means that you can find their contact details at the back of the book.



Introduction

'All the time you keep hoping that the doctors can say what is wrong and that there is something they can do and your child will suddenly catch up and be able to do all the things that other children do.' (Mother)

There are many reasons why children are born with disabilities and/or health needs. These include:

- difficulties during the pregnancy, including infections in the mother
- prematurity
- environmental problems
- genetic disorders
- **asphyxia**, a lack of oxygen, or trauma during or shortly after birth.

If you would like more information about genetic disorders then please refer to part 7 of **Contact a Family**'s 'About Diagnosis' information pack for parents. This is a pack of useful leaflets giving information on various aspects of diagnosis. You can obtain a pack by getting in touch with **Contact a Family** using the contact details at the back of this booklet.

Why do parents feel a diagnosis is important?

It's natural that parents want to know the cause of a disability in their child or an identified need for support. Without a clear diagnosis, it can feel like you're in limbo, not knowing what's happening to your child or what the future holds. It can also feel frightening if you don't know how a disorder might progress.

Many parents describe the feeling of frustration when their child is referred from one specialist to another, desperately seeking a diagnosis. Without a diagnosis you may feel unsure about where to get information and support. Finding ways around the 'system' can be confusing and parents often worry that their child will miss out on appropriate services because they don't have a diagnosis.



Why are some disorders so hard to diagnose?

In many cases it is almost impossible for a paediatrician to single out a specific cause, and a child may have a number of problems that do not fit into any one disorder. Sometimes parents who have a child with an apparently obvious disorder can discover that the cause is quite different from what they believed it to be.

There are a number of reasons why making a diagnosis is difficult:

- Doctors are now seeing a large number of children with **rare conditions**, which may only affect a small number of children. It's harder for doctors to diagnose a condition they've never seen before, and where there are very few studies that would make it possible to compare the features of your child's difficulties with other cases.
- Many disorders have quite similar features and symptoms, which can make it difficult to be accurate about a diagnosis.
- Some children will have a number of problems that do not fit into one specific disorder.
- There are substantial variations in the degree to which a child might be affected by a disorder, which might add to the problem of making a diagnosis.
- Certain identifying features may not appear until your child is older; this may result in a late diagnosis or even a change in diagnosis.
- For many disorders we still do not know the cause, and even when children are in the care of the best medical experts, a diagnosis is not made.

If you feel strongly that all avenues to getting a diagnosis have not been explored, you should certainly discuss this with your child's doctor and request a second opinion. However, sometimes everything that can be done has been done and you are still left with no diagnosis.

New syndromes are being identified

Another factor that contributes to the difficulty of diagnosis is the large number of syndromes that are being identified. Parents who have been told previously that their child simply has developmental delay may be presented with a different number of syndromes suggested as possible diagnoses. This can raise hopes of a precise diagnosis, but it can still take some time to find the right specialist.

'I'm tired of having to explain to people that my child isn't naughty but has an unnamed condition' (Mother)

Does it matter whether you get a diagnosis or not?

Not having a diagnosis may matter very much to you as a parent and it may matter to your child as they get older, so they can understand why they are different. However, for many practical purposes, it doesn't make any difference whether you have a diagnosis or not. This is because:

- Treatment, therapy or teaching should be tailored to your child's needs, not to the name of their disorder.
- You're entitled to have a social services assessment of your child's needs and of your needs as a parent or carer, whether your child has a named diagnosis or not.
- You're entitled to receive benefits such as **Disability Living Allowance** on the basis of the difficulties that your child has and the support they need. Entitlement does not depend on being able to name the disorder your child has. Find out more about this in the [Early Support background information booklet on Financial help](#).
- Your child is entitled to have extra or different support to help them at school, if they need it. This does not depend on knowing the cause of their learning difficulties.



The Disability Discrimination Act protects young children without a diagnosis who require care and additional support. You should be able to receive exactly the same support for your child as a child with a diagnosis. Legal jargon and technical language in documents that outline your rights can be confusing. If you have any questions about your child's entitlement to care and support, please ring the **Contact a Family** helpline (contact details at the back of this booklet).

'I decided it was time to accept that my daughter is unique. Now I'm not as fixated on the idea of a diagnosis as a solution, I can get on with my life. We just have to deal with each new issue in the best way we can.' (Mother)

A diagnosis may not be needed for treatment

It is not always essential to know the cause of a disability or condition to treat its symptoms. Many aspects of a disorder with or without a diagnosis can be treated to a high standard and individuals lead a good quality of life.

'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.' (Mother)

Where to get support, if you don't know why your child needs help

'We use a local group for special needs families, which is excellent.' (Father)

Many areas in the UK have a local parents' support group where families of children with all kinds of disabilities come together for mutual support and contact. It might be helpful to find out if there's one near you.

Even if you had a diagnosis, it's unlikely that another child in the group would have the same disorder. However, a lot of the issues you face on a day-to-day basis will be familiar to other parents and they often have practical advice to share.

Local groups have the advantage of meeting regularly and locally, which can be important in providing a support network if you need one. Another advantage is that other members can pass on information about support and services that are available in your area and that they have already used.



Voluntary organisations

Voluntary organisations are usually charities that provide help and advice. Find out if there are any that operate locally and what they can offer. Or contact the following organisation if you are looking for information and help.

Contact a Family

Contact a Family provides support, advice and information for families with disabled children, no matter what their disorder or disability. **Contact a Family** provides advice about financial and practical help as well as information on medical disorders and disabilities. They also put families in touch with others through support groups and one to one linking, assist parents to develop their own support groups and provide a voice to raise awareness and campaign for families.

The **Contact a Family** website contains all publications, also available in paper format, including the Contact a Family Directory.

Contact a Family

209–211 City Road
London
EC1V 1JN

Helpline: 0808 808 3555

Textphone: 0808 808 3556

Free for parents and families 10am–4pm, Monday to Friday and Monday evenings from 5.30–7.30 pm.

Tel: 020 7608 8700

Fax: 020 7608 8701

Web: www.cafamily.org.uk

Email: helpline@cafamily.org.uk

About Early Support

Early Support is the Government's programme to improve the quality, consistency and coordination of services for young disabled children and their families across England. **Early Support** is funded and managed by the Department for Children Schools and Families (DCSF) and is an integral part of the wider Aiming High for Disabled Children (AHDC) programme, jointly delivered by DCSF and the Department of Health. The AHDC programme is seeking to transform the services that disabled children and their families receive.

Early Support is targeted at families with babies or children under five with additional support needs associated with disability or emerging special educational needs although the principles of partnership working with families can be applied across the age range. This partnership working between families and professionals means that families remain at the heart of any discussions or decisions about their child – their views are listened to and respected and their expertise is valued by the professionals working with them.

To find out more about the **Early Support** programme and associated training or to view or download other materials produced by the programme, visit www.dcsf.gov.uk/everychildmatters/earllysupport

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular disorders or disabilities. This edition of the booklet up-dates information and incorporates comments from those who used the material in 2004-2009.

The other titles in the series are:

Autistic spectrum disorders (ASDs) and related conditions (ES12)

Deafness (ES11)

Down syndrome (ES13)

Multi-sensory impairment (ES9)

Speech and language difficulties (ES14)

Visual impairment (ES8)

If your child has a rare condition (ES18)

Learning disabilities (ES15)

Three additional Information for parents' booklets, one on Sleep, one on Neurological disorders and one on Behaviour will be available by Spring 2010.

Other **Early Support** information about services is available separately, or as part of the **Early Support Family pack**. The Family pack helps families who come into contact with many different professionals to co-ordinate activity and share information about their child through the first few years of life, using a **Family file**.

These are resources that families say make a difference. If your family is receiving regular support from professionals, please feel free to ask them about the Early Support family pack. It may help and is available free of charge.

This edition of the **Information for parents 'When your child has no diagnosis'** booklet is an up date of previous information. **Early Support** would like to thank the many families and professionals that have been involved in development of these resources and to thank Contact a Family and all the parents and families who were involved in producing this material for their help in writing and more recently revising this booklet.

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Tel: 020 7608 8700

Fax: 020 7608 8701

Web: www.cafamily.org.uk

Email: helpline@cafamily.org.uk

Copies of this publication can be obtained from:

DCSF Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ

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www.dcsf.gov.uk/everychildmatters/earllysupport

We acknowledge with thanks the contribution of the following organisation to the production of this resource.

contact a family
for families with disabled children