

Early Support

Helping every child succeed

Information for parents

Does your child have a learning disability?



About this publication

This is a guide for parents with young children who have recently been told that their child has a learning disability, or who are in the process of getting an assessment and are concerned about their child's development.

It was developed by the [Early Support](#) programme in partnership with [Mencap](#), in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content and the 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.

To find out more about [Early Support](#), visit www.dcsf.gov.uk/everychildmatters/earllysupport

Where words are printed in colour and italics, *like this* it means that a parent of a child with a learning disability said it.

Where a word or phrase appears in colour, *like this*, it means you can find an explanation of the word in the text that surrounds it, that the contact details for the organisation or agency identified are listed in the Useful organisations and sources of information section or that you can find out more in the Who can help? section.



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Introduction

Why is my child developing more slowly?

There are all sorts of reasons why children may not reach the milestones expected for their age. If you're worried about your child then it is best to go and see your doctor. It is possible your child has a learning disability, but you may find they are just taking their time.

This booklet can help you find out more about learning disability and how you can help your child if they have one.

What is a learning disability?

A learning disability is not an illness or a disease.

The term **learning disability** describes significant delays in a child's development. In a child's early years, it's unusual for professionals to use the term 'learning disability'. You are more likely to hear terms like 'delay', 'developmental delay' or 'special needs'.

A learning disability may occur on its own or alongside sensory or physical conditions or medical conditions like epilepsy. For some children (for example, children with Down syndrome), there is a genetic basis for their learning disability. However, for many children the causes of their learning disability are never known.

Children with a learning disability find it harder than others to learn, understand or communicate. A learning disability can be mild, moderate or severe. As adults, some people with a learning disability need support with things like getting dressed, going shopping, or filling out forms. But others do not need very much support in their lives.

People who have a severe, or profound, learning disability and a physical disability may need a lot of support 24 hours a day. This is known as **profound and multiple learning disabilities (PMLD)**.

Learning disability is one of the most common forms of disability in the UK. 1.5 million people in the UK have a learning disability – around 3 in 100 people. Around 200 babies are born with a learning disability every week.

If your child has a learning disability, there is a great deal that can be done to help them lead a fulfilling and valued life.



How do I know if my child has a learning disability?

For a small number of children, it's obvious from the time of birth, or shortly after birth, that they will almost certainly have a learning disability. For example, if a child is diagnosed with Down syndrome they are likely to have a learning disability as well. But for other children, it may not be immediately obvious.

What to look out for

Every child's learning disability differs. But here are some examples of how a child may develop more slowly than others their age:

- Babies may have trouble nursing (for example sucking or digesting).
- In early stages, children may show delays sitting and standing.
- Pre-school children may be slow to talk, have difficulty pronouncing words and short sentences or learning new words.
- Children of school age may have difficulty reading and writing and understanding information or instructions.

Many children experience delays, like these, in reaching the milestones expected for their age, but this does not always mean they have a learning disability. It is best to seek advice if you're at all worried.

Talk to your health visitor or GP

If your child seems to be developing more slowly and you'd like some advice, talk to your **health visitor** or your **GP** first of all. They will talk through your concerns with you and may be able to reassure you. They may suggest that you monitor your child's progress together or they may refer you to a specialist. This would usually be a paediatrician (a doctor who specialises in working with babies and children).

Keep up to date with your child's routine checks

Sometimes, a learning disability isn't obvious to parents or doctors and it's only during routine developmental checks that concerns about learning disability come up. Routine checks focus everyone's attention and can lead to your child's progress being monitored over a period of weeks or months, or a referral to a specialist.



What does a learning disability mean for my child?

Learning disability is a very broad term and disabilities range from mild to moderate to severe. In your child's early years it's very hard to predict how they will develop - much depends on how you are supported as a family, and the quality of services you have access to.

Every child's learning disability is different

What learning disability means for your child will be individual to them.

Most children with a learning disability experience delay in more than one area. For example, their communication may develop slowly, as well as their progress in learning to dress and undress.

For some children, development can be 'bumpy', so they make good progress for several months and then level off for several months.

A significant number of children with a learning disability also have sight or hearing problems, or other physical conditions that affect their overall development.

Whether their learning disability is mild, moderate or severe will shape the level of care they need throughout their life.

Every child is an individual

Many people with a learning disability live independent lives. It is important to remember that people with a learning disability are individuals - with their own personalities, ambitions, likes and dislikes.

A learning disability does not prevent someone from learning and achieving a lot in life, given the right support.

What can I do to help my child?

There are plenty of things you can do to help your child with a learning disability.

Much of what you can do is the same as you would do for a child without a learning disability. The main difference is the length of time it takes for your child to move from one stage of development to another.

As your child develops and you learn more about them, you will be able to judge how you can help them more specifically. But here are a few things you can do.

1. **Get help early** – the more support your child has, the more progress they will make. Speak to your **GP** first and don't be afraid to ask questions.
2. **Get the right support** – get to know which health professionals to go to for your child. Your **GP** might refer you to specialists. It may take some time but you will learn which professionals are right for your child. There are lots of people who can help you and you'll find details later on in this booklet.
3. **Learn about your child's condition** – if you have a diagnosis. Ask your doctor, call helplines (there are more details in the Useful organisations and sources of information section later in this booklet) and speak to other parents. The more you find out, the more prepared you will be.
4. **Get to grips with the difficulties your child has** – again this may take time and several sessions with a professional. Listen to your child carefully and really try to understand what they're trying to tell you, even if they're not using words.
5. **Include and encourage your child** – include them in family life, in your conversations and activities. Encourage them to communicate and participate. Read to them and with them.
6. **Be patient** – children with a learning disability can and do learn, it just takes them a little more time.
7. **Focus on your child's strengths** – reward and praise them when they do well. Plan activities that you know they are good at to give their confidence a boost.
8. **Change how you communicate** – if your child has difficulty with speech, perhaps take some training in different ways of communicating, such as **Makaton**. As they get older, show them how to do something rather than telling them. Get down to their level – speak in short instructions ('put your jumper on' not 'put your jumper on and get your lunchbox').
9. **Practice, practice, practice** – your child may need more time to learn new skills, so practice with them regularly. Repetition will help them learn.
10. **Take care of yourself** – if you're fit and healthy you will be able to help your child more effectively.



Remember...

Although your child may have a learning disability, they will still like the same things as other children – making friends, getting out and about, playing and learning.

Children with a learning disability can use all the same services as other children, for example sessions for young children held at the local swimming pool, leisure centre or playgroup. So don't be afraid to take them. You may need some support, but it's important to keep in mind that your child will enjoy and get so much out of playing and interacting with other children.

Who can help?

There are all sorts of people who can help you and your child – and your whole family. As well as relatives, friends and neighbours, you'll find a range of professionals and organisations that can give you advice, counselling and very practical help.

General practitioners (GPs) are family doctors who work in the community. They are the first point of contact for many families and provide a general child health service, including immunisations. Your GP will be able to point you in the right direction and can also refer you to a range of specialists such as paediatricians, learning disability nurses, child development teams or therapists.

Health visitors are health professionals who visit the family home in the early years of a child's life to check on their health and development.

You should automatically receive a visit from a health visitor when your child is born. If you don't, your GP can arrange one for you.

Health visitors can give you help and advice about the care of very young children, child development, feeding and sleep, behaviour and safety. They can also help you find out about childcare and specialist help for your child.

Your health visitor is there for the whole family and can help you think about what you all need.

Learning disability nurses are specialist nurses who work with children and adults with a learning disability and their families. Your GP can refer you if you need one.

Paediatricians are doctors who specialise in working with children who are ill or disabled, and concentrate on their health and development. Your GP can refer you if you need one.

Paediatricians may see your child to assess their learning disability or to monitor their health and progress. They can offer advice, information and support about any medical condition(s) your child has.

They may also refer your child to other specialists, for example a clinical psychologist or a child development centre, where their health, social and educational needs will be considered in detail.

Some areas also have community-based paediatric nurses who can visit you at home and work closely with the whole family.

Clinical psychologists are health professionals who can help your child with specific problems learning new skills and help them overcome behaviour difficulties. Your GP or paediatrician can refer you if necessary.



Clinical psychologists will assess the difficulties your child has and put together a tailored programme of treatment for them that can include therapy, counselling and advice.

Therapists are health professionals who work with all kinds of people, including children with a learning disability. There are a number of different types of therapist, and your GP can refer you to the most suitable one for your child. As well as your GP, you can ask social services for an appointment.

- **Speech and language therapists** help with communication. They can offer support and advice to parents of children with any type of communication problem and help children develop their communication, language and speech. They can also help children who have difficulty swallowing and feeding.
- **Physiotherapists** can help your child with their movement. Your GP, a family member, friend or carer can refer you and your child to a physiotherapist. Physiotherapists will look at any problems your child has with movement and set a programme of physiotherapy that will help them. For example they might improve a child's head control or their ability to sit with support – helping them to prop themselves up on their hands.
- **Occupational therapists** can assess a child's skill at play, school and day-to-day tasks to help them improve. For example, they can help children with a learning disability develop hand-to-eye co-ordination and better grip with building blocks, so they can grasp toys and get more out of play.

Local authorities can help you and your family get the support you need. Your local authority's Family Information Service can put you in touch with other helpful agencies and parent support groups. They will also have information about childcare, opportunity groups, nurseries and children's centres.

Your local authority's social services will be able to put you in touch with a social worker. A social worker may assess your child's needs and whether your family needs any extra support.

Charities and other organisations can provide information and put you in touch with local parent support groups. There is a list of organisations, with contact details, at the back of this booklet.

What other families found helpful

“My advice for other parents would be: don't panic, start making plans for every stage of your child's life and keep these plans up to date. Fight for everything your child needs and deserves.”

Give yourself time

“You need to take time to come to terms with it all, to be angry and upset, but then you have to move on...”

It is so important to take time to understand and adjust to your new situation. It may not be what you expected and it can be difficult to come to terms with. Talk to your family and friends, or a counsellor if it will help. Then you can start concentrating on getting the best support for your child.

Also, take time for yourself (and your partner if you have one). Give yourself breaks so you have time to refresh and relax, and you can carry on supporting your child the best you can.

Don't go through it alone

“I found out about my local Mencap group, and their friendship network and support were my salvation. I am still a member all these years later.”

“We also built up a network of parents who are in a similar position to us.”

As well as having supportive family members and friends, lots of families have found that talking to others in the same situation helps a lot. If you are referred to a parent support group, or you find one yourself, give it a try. Sharing your experience and comparing it with other parents' experiences can stop you feeling isolated, help you feel supported and make things easier for you and your family. Other parents may also be able to recommend groups or activities that you haven't tried.



Look for local support

“We took it upon ourselves to get in contact with other professionals through social services. We started building up good contacts with local voluntary groups. We also got in touch with other parents and carers, and our sons attended a siblings club for a while.”

There will be a range of early years services, for example children’s centres, in your area. Family-friendly services understand your concerns, can offer advice and support and most importantly, value your child as an individual. They offer support for your other children too, who might need help to adjust.

Find out what you’re entitled to

“For us, having control over our own finances through direct payments has made a huge difference as it means we can decide what support we want for our daughter.”

Your local authority can tell you whether you are entitled to direct payments as a family. If you are, then instead of using local authority services, you will get money so you can buy the specific support your family needs.

There are various ways to get financial help if you need it, such as tax credits. Find out more about some of the financial help available in the [Early Support background information booklet](#) on [Financial help](#).

Work with specialists to help you and your child

“We had the support of SENCO from when our son was first diagnosed.”

“I was given support from the portage teacher. That was a turning point for me – I was being given tools to help my child develop and I started to understand her needs.”

Working with professionals can not only help your child develop, it can also make you feel more confident. You will get to know what difficulties your child has and how you can support them at home.

What will I need to think about as my child gets older?

Pre-school education

From a very young age, children with a learning disability benefit from learning through play. This type of learning starts at home. In most parts of the country there are advisers who can help you with this. They are usually called pre-school teachers or **Portage** workers. They can set learning goals and help you work towards them at home.

Portage services

Portage is a home visiting educational service for pre-school children and their families who need extra support. These services are generally provided by your local education authority.

Early years centres

Your child is entitled to part-time early years education. You can find out more from your local Family Information Service. If your early years centre feels your child needs extra support, they should be able to help.

Choosing a school

Choosing a school for your child is a big decision for any parent. The first step is to find out exactly which schools are available in your area - you can get this information from your local authority. A full list of local authority website addresses is available on the Directgov website.

Your local authority can also put you in touch with the local **Parent Partnership Service** who can give you information and advice about education locally (we've also included their national website in the useful contacts section).

Local education services

You will probably find that your child will get the support they need from their local primary school, or mainstream school. However, if your child has complex needs you may want to consider a school that caters only for children who need more specific support. Your options also depend on whether your child has a statement of special educational needs.



Assessments

Your local authority's education department may assess your child to make sure they get the right education. If the local authority thinks your child will need a lot of extra support they will issue a statement of special educational needs – a document that describes in detail your child's needs and what help will be provided for them.

A statement may be recommended by your local authority, your health authority or social services. You can also request one if you are worried about your child's development. Find out more on the [Mencap](#) website, *Families* section, under *Ages and stages 0-5*. Further information about statements can also be found in the [Early Support background information booklet](#) on [Statutory Assessment: Education](#).

Your child may also have a [Common Assessment Framework](#) assessment. This is an assessment that is used by a wide range of practitioners, working together. It looks at all aspects of your child's life to make sure they get the help they need.

If you want to go back to work

You might want to go back to work or get into training. Your local [Family Information Service](#) will be able to advise you about childcare options and any tax credits that may be available to you. You can contact them through your local authority offices, the local authority website or the National Family Information service website – www.nafis.org.uk.

Extra help

You may want to think about whether your local authority could help. This could be help in your home, or maybe the opportunity for your child to spend a few hours being looked after away from home. You can arrange and pay for these services yourself. If you want your local authority to arrange and pay for them, contact your local authority social services department to see if you are eligible for help.

Dealing with prejudice

As your child gets older, they may come across people with challenging attitudes and behaviour. If your child has been valued and supported in their early years, it will help them deal with this kind of prejudice and discrimination. There is also plenty of help available from support groups and other organisations like [Mencap](#).



Useful organisations and sources of information

Afasic

A parent-led organisation representing children and young people with speech and language impairments. It works for their inclusion in society and supports their parents and carers. Afasic is a membership organisation providing a telephone helpline, conferences, publications and support through local groups.

Afasic
1st Floor
20 Bowling Green Lane
London EC1R 0BD

Helpline: 0845 355 5577
Tel: 020 7490 9410
Fax: 020 7251 2834

Email: info@afasic.org.uk
Web: www.afasic.org.uk

Children Today

Children Today provides grants for vital, life-changing equipment for children and young people with sickness and disability across the UK.

Children Today Charitable Trust
The Moorings
Rowton Bridge
Christleton
Chester CH3 7AE

Tel: 01244 335622
Fax: 01244 335473

Email: info@childrentoday.org.uk
Web: www.children-today.org.uk

Contact a Family

Contact a Family is a UK-wide charity providing support, advice and information for families with disabled children. They run a helpline for family members. Contact a Family can also help you get in touch with other parents of disabled children living near you.

Contact a Family
209-211 City Road
London EC1V 1JN

National helpline (freephone): 0808 808 3555
Textphone helpline (free for parents and families): 0808 808 3556
Tel: 020 7608 8700
Fax: 020 7608 8701

Email: helpline@cafamily.org.uk
Web: www.cafamily.org.uk

Down's Syndrome Association

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome. They also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination. A wide range of Down's Syndrome Association publications can be downloaded free of charge from their website. Printed copies are available for a small fee. Single copies of most leaflets and information sheets are available free of charge to members.

Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington TW11 9PS

Tel: 0845 230 0372
Fax: 0845 230 0373

Email: info@downs-syndrome.org.uk
Web: www.downs-syndrome.org.uk



Every Child Matters

Every Child Matters is a shared programme of change to improve outcomes for all children and young people. It is part of the government's vision of radical reform for children, young people and families.

Every Child Matters
Department for Children, Schools and Families
Sanctuary Buildings
Great Smith Street
London SW1P 3BT

Tel: 0870 000 2288
Fax: 019 2879 4248

Email: info@dcsf.gsi.gov.uk
Web: www.dcsf.gov.uk/everychildmatters

The Makaton Charity

Makaton is a recognised approach to teaching communication skills for those with communication and learning difficulties of all ages. Makaton provides access to education, training and public information through the use of symbols and signs with speech. Resources, training and translation are also available.

The Makaton Charity
Manor House
46 London Road
Blackwater
Camberley
Surrey GU17 0AA

Tel: 01276 606760

Email: info@makaton.org
Web: www.makaton.org

Mencap

Mencap is the UK's leading learning disability charity. Everything they do is about valuing and supporting people with a learning disability, their families and carers.

They work with people with a learning disability across England, Wales and Northern Ireland to change laws and challenge prejudice. And the services they provide, in things like housing, employment, education and personal support, give thousands of people the chance to live their lives as they choose.

Call their helpline or visit their website for factsheets, guides, useful contacts, information about funding, services and Mencap carer's network and to read blogs from other families.

Mencap
123 Golden Lane
London EC1Y 0RT

Learning Disability Helpline (freephone): 0808 808 1111
Learning Disability Minicom Helpline (freephone): 0808 808 8181

Email: information@mencap.org.uk
Web: www.mencap.org.uk

National Parent Partnership Network

Parent Partnership Services (PPS) are statutory services offering information and advice to parents and carers of children and young people with special educational needs (SEN). PPS are also able to put parents and carers in touch with other relevant local and/or national organisations.

National Parent Partnership Network
Council for Disabled Children
National Children's Bureau
8 Wakley Street
London EC1V 7QE

Tel: 0207 843 6058
Fax: 020 7278 9512

Email: nppn@ncb.org.uk
Web: www.parentpartnership.org.uk

Information for parents
Does your child have a learning disability?



National Portage Association

A registered charity established in 1983 to offer support and information to parents and professionals involved in Portage, a home visiting educational service for preschool children with additional support needs and their families.

National Portage Association
Kings Court
17 School Road
Birmingham B28 8JG

Tel: 0121 244 1807

Email: info@portage.org.uk

Web: www.portage.org.uk

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 conditions or disabilities. This is the third edition of the booklet, which up-dates information and incorporates comments from those who used the material in 2004-2009.

The other titles in the series are:

Cerebral palsy (ES10)

Down Syndrome (ES13)

Autistic spectrum disorders and related conditions (ES12)

If your child has a rare condition (ES18)

Deafness (ES11)

Speech and language difficulties (ES14)

Visual impairment (ES8)

Multi-sensory impairment (ES9)

When your child has no diagnosis (ES16)

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.

Early Support would like to thank the many families and professionals that have been involved in development of these resources and to thank **Mencap** 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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Email: information@mencap.org.uk
Web: www.mencap.org.uk

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Sherwood Park
Annesley
Nottingham NG15 0DJ

Tel: 0845 602 2260
Fax: 0845 603 3360
Textphone: 0845 605 5560

Please quote ref: ES15

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www.dcsf.gov.uk/everychildmatters/earllysupport

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