

## Information for parents

### Learning disabilities





## What is a learning disability?

Learning disabilities are the most common form of childhood impairment: 1 in 20 children have a learning disability of some kind. The term 'learning disability' is very wide and covers any development that is significantly behind what is expected for a particular age. Learning disability may occur on its own or in addition to sensory or physical impairments or medical conditions like epilepsy. For some children (for example, children with Down's syndrome), there is a genetic basis for their learning disability. However, for most children the causes of learning disability are never known.

A learning disability is a lifelong condition. Although there are no cures, there is a great deal that can be done to help children with a learning disability lead fulfilling and valued lives.

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

- Many children experience delays in reaching the milestones expected for their age, but this does not always mean they have a learning disability. It's worrying if your child seems to be slow to develop in any way and the first step should always be to see your **health visitor** or doctor (**GP**) to talk about your concerns. They may be able to reassure you or suggest that you monitor your child's progress together with them. Sometimes GPs recommend a referral to a specialist, usually a **paediatrician** (a doctor who specialises in working with babies and children).
- Sometimes, it's when routine developmental checks are being carried out with your child that concerns about learning disability are raised. Routine checks focus everyone's attention and may lead to monitoring progress over a period of weeks or months. Sometimes they lead to a referral to a specialist.
- 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. Some syndromes mean that all children with this syndrome have a degree of learning disability – for example, Down's syndrome.
- In a child's early years, it's unusual for professionals to use the term 'learning disability' and you are more likely to hear terms like 'delay', 'developmental delay' or 'special needs' being used instead.



## What does a learning disability mean for my child?

- Learning disability is a very broad term, and in your child's early years it's very hard to predict how they may develop in the future. Much depends on how you are supported as a family and the quality of services that are provided to help you.
- Most children with a learning disability experience delay in more than one area. For example, communication may develop slowly as well as learning to dress and undress. For some children, their development is 'bumpy', so that 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 hearing, visual or physical impairments which affect their overall development.

## What can I do to help my child?

Children with a learning disability need the same basic things as other children. They need:

- to be valued as a child first and foremost
- to be safe and healthy
- to be able to communicate with you and other people
- to move around and get out and about
- to play and make friends
- to learn and eventually, go to school.

Many of the ways of helping your child with a learning disability are exactly the same as for other children. Strategies that other parents find useful will help. The main difference is likely to be that you are using them with your child later than you might have expected and it will take longer and need more repetition before your child moves from one stage of development to another.

There may be times when you need information or support in finding the best way to help your child. The first step is to think about the help or support that you think you need and what the priorities are for your family. Every child is different and every family is different. What will help you and your family and what is available locally varies. It may help to talk through what you want for your child with your family, with close friends or with professionals like your GP, before approaching specialist services.

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. It's important to keep in mind that your child is a child first and foremost and to trust your own judgement when you are offered help.

Only you know what is right for your child and your family.

## Who can help?

As well as your family, friends and neighbours, a range of professionals and organisations can help. These include:

### General practitioners (GPs)

GPs are family doctors who work in the community. They are the first point of contact for many families. They provide a child health service, including immunisations, and can refer your child to a paediatrician, learning disability nurse or therapist, if this is needed.

### Health visitors

A health visitor is a health professional who visits family homes in the early years to check on children's health and development. They can give you help and advice about the care of very young children, child development, feeding and sleep, behaviour and safety. You should automatically receive a visit from a health visitor, as all families are visited in the early years. If you don't, they can be contacted through your GP. Health visitors 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**

**Learning disability nurses** are specialist nurses who work with children and adults with a learning disability and with their families. They can help you find services for your child and also support for you as a parent.

### **Paediatricians**

**Paediatricians** are doctors who specialise in child health and development. They may see your child for an assessment or to monitor their health and progress. They may also refer your child to other specialists, for example a **clinical psychologist**. Paediatricians can offer advice, information and support about any medical condition(s) your child has.

### **Clinical psychologists**

**Clinical psychologists** are health professionals who can help your child with specific problems in learning new skills and can help them overcome behaviour difficulties.

### **Therapists**

**Therapists** are health professionals who work with children with learning disabilities in various ways:

- **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.
- **Physiotherapists** help with movement.
- **Occupational therapists** help with everyday tasks and equipment.

**Social workers** can help you and your family get the support you need and put you in touch with other agencies and parent support groups.

**Voluntary organisations** are usually charities, and can provide information and put you in touch with local parent support groups. At the end of this booklet is a list of organisations, with contact details.

## What other families say helps

Other families say the following things help:

- Having family and friends who accept your child and offer you support
- Taking time for yourself (and your partner, if you have one)
- Good-quality information and advice that allows you to make informed choices
- Being in touch with other families who have a child with a learning disability
- Family-friendly services that value your child, understand your concerns and support you in helping your child
- Help for other children in the family – everything from being noticed to contact with other children who have siblings with learning disabilities.

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

- 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 help you identify and work toward learning goals at home.

### Portage or Portage services

Portage is a home visiting educational service for pre-school children with additional support needs and their families. These services are generally provided by your **local education authority**, which is responsible for providing education.



- Your child may be assessed to make sure that the right education is provided and this assessment is arranged through the education department of your local authority. They can put you in touch with the local **Parent Partnership Service** who can give you information and advice about education locally. If you are having difficulty finding out about your local Parent Partnership Service, ring the **Contact a Family Helpline** (0808 808 3555). They should be able to help.
- You may want to think about whether family support services would 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 family support services, you will need to contact your local authority **social services department** to arrange for an assessment of your family needs and to see if you are eligible for help.
- You may want to go back to work or get into training. The local **Children's Information Service** will be able to advise you about childcare options and any tax credits that may be available. You can contact them through your local authority offices or the local authority website. For more information, or to get the contact details for your local service:

Tel: 0800 096 0296

Web: [www.childcarelink.org.uk](http://www.childcarelink.org.uk)

- As your child gets older, they may come across people with unhelpful 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.
- Later on, your child may need some information and help in understanding their learning disability. There are a wide range of books and advocacy services that can help.

## Useful organisations and sources of information

### Mencap

Mencap is the UK's leading learning disability charity working for people with a learning disability and their families and carers. They fight for equal rights, campaign for greater opportunity and challenge attitudes and prejudice. Mencap provides advice and support to meet people's needs throughout their lives, and has local societies around England.

### Mencap National Centre

123 Golden Lane  
London  
EC1Y 0RT

Learning Disability Freephone Helpline: 0808 808 1111

Learning Disability Freephone Minicom Helpline: 0808 808 8181

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

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

### Down's Syndrome Association

The Down's Syndrome Association provides information, counselling and support for people with Down's syndrome, their families and carers, as well as being a resource for interested professionals. They strive to improve knowledge of the condition and champion the rights of people with Down's syndrome.

Langdon Down Centre  
2a Langdon Park  
Teddington Middlesex  
TW11 9PS

Tel: 0845 230 0372

Fax: 0845 230 0373

Email: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

Web: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)



### Contact a Family

Contact a Family helps families who care for children with any disability or special need. They are a main source of information about rare disorders and are able to assist affected adults as well as children.

209–211 City Road  
London  
EC1V 1JN

National Freephone Helpline: 0808 808 3555  
Textphone Freephone Helpline: 0808 808 3556  
Tel: 020 7608 8700  
Fax: 020 7608 8701

Email: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)  
Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

### Afasic

Afasic is a parent-led organisation to help children and young people with speech and language impairments and their families. It works for their inclusion in society. It's a membership organisation providing a telephone helpline, conferences, publications and support through local groups.

2nd Floor  
50–52 Great Sutton Street  
London  
EC1V 0DJ

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

Email: [info@afasic.org.uk](mailto:info@afasic.org.uk)  
Web: [www.afasic.org.uk](http://www.afasic.org.uk)

The **Early Support Pilot Programme (ESPP)** is a Government programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. ESPP promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit [www.espp.org.uk](http://www.espp.org.uk)

ESPP is putting into practice the principles outlined in the Government guidance document *Together from the Start* which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

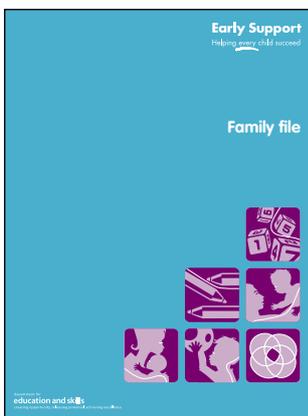
This booklet is one in a series produced by ESPP in response to requests from parents and voluntary organisations for better information for parents. ESPP has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles are currently available:

Autistic spectrum disorders (12)	Cerebral palsy (10)
Learning disabilities (15)	Down's syndrome (13)
If your child has a rare condition (18)	Multi-sensory impairment (9)
Speech and language difficulties (14)	Visual impairment (8)
When your child has no diagnosis (16)	Deafness (11)

Copies of these booklets 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](mailto:dfes@prolog.uk.com)

Please quote the appropriate reference number.



ESPP has also produced a **Family Pack**, which supports families through the first years of their children's lives. The Pack contains background information about the services you may need, the help you are entitled to and a **Family File** designed to help co-ordinate any support being provided for your family. They are resources that other families have said would make a difference. If you and your child are receiving regular support from a professional or range of professionals, please feel free to ask them about the **Early Support Family Pack**, which may help and which is available free of charge.

ESPP would like to thank all the parents and families involved in the production of these resources.

ESPP would also like to thank **Mencap** for their help in writing, consulting upon and producing this resource.

**Mencap** is the UK's leading learning disability charity working for people with a learning disability and their families and carers. They fight for equal rights, campaign for greater opportunity and challenge attitudes and prejudice. They provide advice and support to meet people's needs throughout their lives.

123 Golden Lane  
London EC1Y 0RT

Tel: 0808 808 1111 (Learning Disability Helpline)

Textphone: 0808 808 8181

Fax: 020 7608 3254

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

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

**MENCAP**  
*Understanding learning disability*

Copies of this booklet 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](mailto:dfes@prolog.uk.com)

Please quote ref: ESPP15

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**MENCAP**  
*Understanding learning disability*