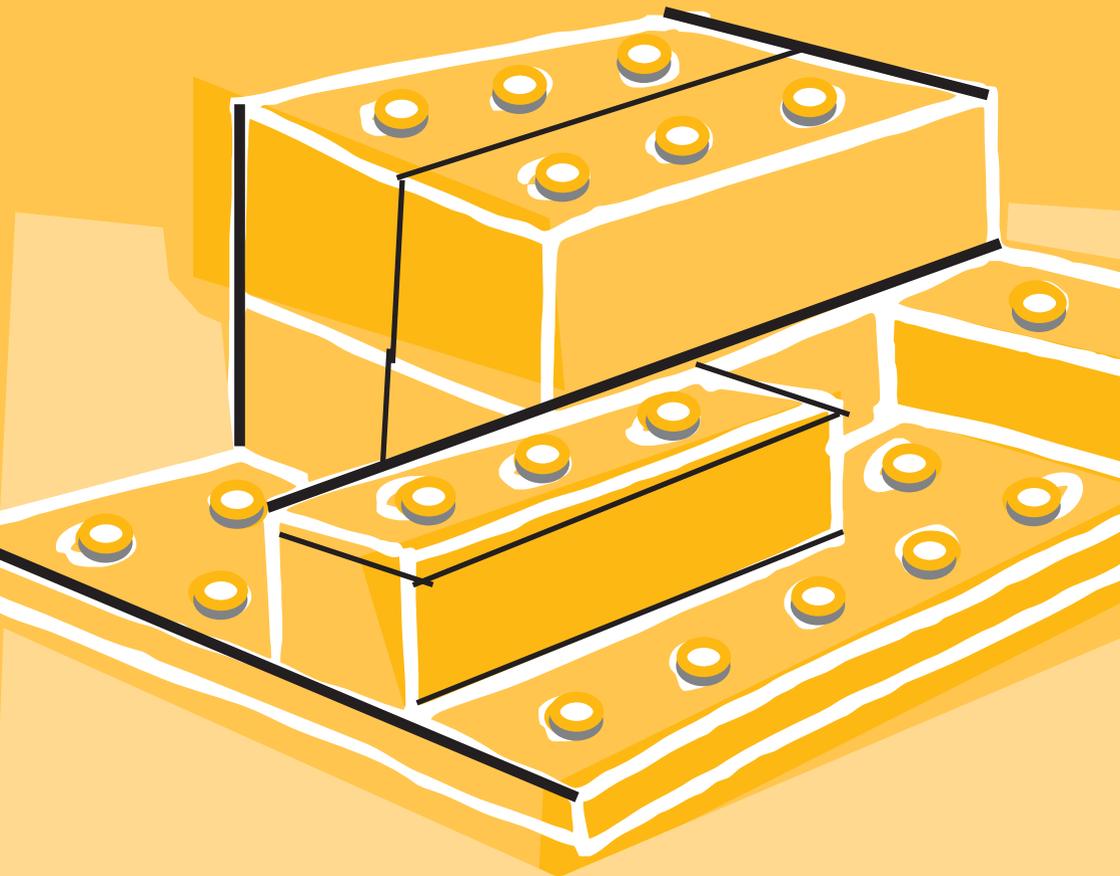




For better
mental health

Understanding learning disabilities



This booklet is aimed at people who have a learning disability, their families and friends. It explains what it means, what some of the causes are, and what the effects may be. It also outlines some of the different kinds of support that are available to people who have these problems and their families, and how to access this.



What is a learning disability?

Someone who has a learning disability will have certain limitations on their ability to think (known as an impairment of intellectual ability). This limit might be hardly noticeable or very severe, and anywhere in between. In the past, there have been many other terms used, such as mental handicap and retardation. Those concerned find these labels offensive, and prefer to be described as having learning disabilities, or special needs.

These problems are often confused with mental illness, but they are quite different. A learning disability is a lifelong condition, which starts very early on. Unlike a mental illness, it doesn't cause an unstable personality, temporarily distort a person's view of the world, change dramatically or 'get better'. Although a learning disability can never go away, there's a great deal that can be done to support and enable people to lead as full and ordinary a life as possible.



Are there different disabilities?

There are many different kinds. In fact, this term covers such a vast range of people, with such different abilities and difficulties, that it doesn't really tell us very much. Some learning disabilities are well known and easily recognised, such as Down's syndrome. Others are more difficult to assess and diagnose, and many remain unclassified, because so little is known about them.

In any case, it's questionable how helpful these labels are, when they can be applied to so many people with such different lives and abilities.

There are also different degrees of difficulty. At one end of the spectrum are people with very mild disabilities, who can lead ordinary lives, in jobs and relationships, with very little, if any, support. At the other end are those with very profound disabilities, who need a great deal of help to carry out everyday tasks that most of us take for granted.

What causes them?

There are many possible causes, and experts don't yet know about all of them. It's possible that there are a number of contributory factors involved at the same time.

There can be something in a baby's genetic make-up that leads to complications. Sometimes, the baby doesn't develop in the usual way, either because of inheriting certain genes and chromosomes, or just by accident. The best known of these conditions is Down's syndrome, which is more common to children of older parents. There are tests that parents may have during pregnancy, if they want to. This is a controversial issue, because many people with learning disabilities and their families feel that the idea of testing for these conditions reduces the value placed on their own lives.

Other factors during the pregnancy itself also play a part. It's thought that infections and disease, a poor diet and abusing harmful substances (such as drugs or alcohol) can affect the growing baby. Problems may also be caused by an injury to the baby before, during or after delivery. After the birth, infections such as meningitis, head injuries and extreme deprivation can sometimes be responsible.





How is it diagnosed?

Many learning disabilities are diagnosed straight after a baby has been born, or, in some cases, even beforehand, for example by an amniocentesis test during pregnancy. Health visitors and GPs are likely to pick up any undiagnosed problems (depending on their type and cause) during a baby's regular developmental checks. Most babies reach certain milestones (such as babbling, making eye contact and learning new physical skills) at around the same age. If you are concerned that your baby isn't reaching these at the right time, you should discuss this with your GP or health visitor. Sometimes, a problem isn't spotted until someone is older, when it can be diagnosed and assessed through various psychological tests.



What other problems can a learning disability bring?

It may make people more prone to certain conditions that can affect us all. For instance, it's estimated that 80 per cent of people with autism also have some level of learning disability. (See *Further reading*, on p. 14.) Epilepsy is also more common than among the rest of the population. Difficulties with communication can be another problem, particularly if a person's disability is severe. It may be more likely for people with a learning disability to have additional physical disabilities and mental health problems. Some experts feel that it's not surprising that people are more likely to have mental health problems, given the difficulties that they face. However, the majority of people concerned don't have any additional special needs.

Prejudice and discrimination

In the past, society has often treated people with learning disabilities very badly. Misunderstanding and misinformation have kept them apart as a group. Many lived in institutions, under very poor conditions, where they were often neglected or abused.

It's not surprising that people living in these circumstances would sometimes lash out against this abusive system, but, unfortunately, this probably fed the myth that learning disabilities made people aggressive or dangerous. On the other side of this coin was the equally narrow-minded and prejudiced view that anyone with a learning disability was always child-like, happy and loving.

Luckily, those days are now behind us, and people with learning disabilities are properly recognised as a diverse group of unique individuals. The Government now actively encourages people to live in the community, so that they can stay in their own homes in their own neighbourhoods, just like anybody else. It's now accepted that everybody should have the same rights to privacy, to be treated with respect, to conduct relationships, to find meaningful work and to make choices about their everyday lives.

Unfortunately, there are still some people who feel prejudiced against people with learning disabilities, perhaps through ignorance, fear or a lack of experience. Many people with learning disabilities find that society's attitude towards them, and the barriers this produces, actually causes them more difficulties than their disability, although this situation should be improving, gradually.

What is it like to have a learning disability?

How we feel about ourselves is closely linked with how other people feel about us, and this is just as true for someone with a learning disability. He or she may often feel angry, sad, envious and that it's 'not fair'. These feelings are all understandable and should be acknowledged. Sometimes it's too difficult to talk about these feelings within a family and it's better to talk to a trained professional, such as a counsellor or psychotherapist. (See *Useful organisations*, on p. 12, and *Further reading*, on p. 14.)



It's important not to confuse disability with identity; your disability is not who you are. Most people learn to cope with the difficulties they face and go on to lead fulfilling lives. One way of achieving this is to accept that everyone is different and we all have things we can and can't do. By focusing on our abilities and strengths, rather than our disabilities, we are likely to have a more positive and healthy approach to life. Rather than concentrating on the fact that an individual can't talk, for example, it's better to think positively about the other ways he or she can learn to express him- or herself, such as through sign language, symbols or photographs.



What issues might parents face?

Every parent hopes for a perfect baby and, when this isn't possible, it can be a great shock and disappointment. There are often feelings of anger, guilt and grief. If these feelings are not talked about, they can interfere with the developing bond between parents and child. For this reason, it's very important that parents get all the support, advice and counselling they need when a child is diagnosed with a disability. Talk to your GP about this, who should be able to refer you to a counsellor or psychotherapist. Or you could contact one of the specialist organisations listed under *Useful organisations*, on p. 12.

Most relationships between parents and children can get quite complicated at some stage, but it's often more so when the child has a learning disability. It can be difficult for a parent to view the child as growing into an adult. Issues such as independence and sexuality are frequently very hard for parents to cope with. While most of us learn through experience, taking risks and making mistakes, people with learning disabilities are often over-protected and denied these kinds of opportunities. Parents have the difficult task of giving their child the extra help they need, while not helping them so much they hinder them.

A good approach is to think of doing everyday tasks with your child, rather than for them. When this balance is achieved it's called 'enabling'. Everybody has some level of skill that can be developed, if encouraged and nurtured.

Learning to do new things for ourselves increases our self-esteem and makes us all feel better. The learning-disabled person that is supported to be as independent as possible will be happier and more fulfilled as a result. Again, talking these issues through with a counsellor, another learning disabilities professional, or even with other parents who are in the same situation, can be very helpful.

How will it affect the family as a whole?

It's impossible to say how having a child might affect a family, since all children (learning-disabled or not) are individuals with unique needs and strengths. Learning disabilities is a term that covers a vast range of abilities and difficulties. A child with a mild disability may have no other impact on his or her family than you would expect any new addition to make. But a child with a profound learning disability, possibly coupled with a physical disability or other problems (see above), is likely to make a significant difference to the family. This may lead to jealousy between brothers and sisters for all the attention that child receives. In some cases, brothers and sisters might also benefit from talking to a professional, and family therapy or systemic therapy for the whole family group can be extremely helpful.

Despite the added stresses, there can be many unexpected rewards. Your child or sibling may place more demands upon your time and patience than other children, but may also bring extra affection, fun and good humour to your life.

What support can someone expect?

Families can get help and support from education services, social services and local health authorities. Many areas have specialist Community Learning Disability Teams. They consist of a variety of different experienced professionals who, between them, can usually offer advice and help with most difficulties someone may encounter.



As well as having enough emotional and practical help, it's important for parents to get the financial support to which they are entitled. Social services can explore this on your behalf. They can also help you research school, day care or employment options and help with housing issues and finding local respite services that can help families in stressful situations to have a break.

In addition to government agencies, there are many charity and voluntary organisations that can offer different kinds of help to families and individuals. For instance, parents often find a great deal of information and encouragement through talking to other parents who are in the same situation. Many people with learning disabilities also find these kinds of groups or individual counselling very helpful. Organisations such as Mencap, SPOD and Contact a Family can help with this. (For more information, see *Useful organisations*, on p. 12.)

Additionally, there are many organisations specifically concerned with particular difficulties, such as cerebral palsy, Down's syndrome, epilepsy, autism and impaired sight or hearing. (See p. 12.)



What kind of financial help can we get?

People with learning disabilities and their families are entitled to a range of benefits, such as Disability Living Allowance, Disabled Person's Tax Credit and Incapacity Benefit. Children and adults should receive Disability Living Allowance if they need help looking after themselves or getting about (in the case of children, more than would be usual for their age). Since April 2001, the Government has stopped providing what was known as Severe Disablement Allowance.

Looking into what financial help you are entitled to can seem quite complicated and overwhelming. It's possible to find out more about benefits and how to claim them from your local social security office. For your nearest office, look for the display advert under Benefits Agency, in the business numbers section of the phone book. You can also ask your social worker, or one of the voluntary agencies, including the MindinfoLine. (See *Useful organisations*, on p. 12.)

What about schools?



Local authorities are required to provide schooling for all children, whatever their special needs might be. Some parents feel it's important for their child to be integrated into a mainstream school, while others have campaigned to maintain more specialised schools. Most children with learning disabilities are educated in these specialist schools, which are designed to meet their needs.

The 1970 Education Act and subsequent legislation states that children with special educational needs should attend mainstream schools, if their needs can be met there. The Special Educational Needs and Disability Act 2001 makes it unlawful to discriminate against pupils with disabilities in schools and colleges. Local education authorities and schools need to plan access to teaching and learning arrangements, adaptations to the curriculum and staff training.

What kind of help can we get with long-term care?



In 1971, the Government White Paper, *Better services for the mentally handicapped*, recommended the integration of people with learning disabilities into the community, so that it's now more usual for people to live with their families or in smaller residential homes in ordinary neighbourhoods.

The 2001 Government White Paper, *Valuing people*, has emphasised the need to close long-stay hospitals and provide, instead, adequate specialist support to help people with complex difficulties to stay in their own homes and work places. Today, the planning and running of services for people with learning disabilities widely complies with the philosophy of care in the community. However, the standard of care provided in the community can be very uneven, and lack of funding can result in inadequate care. Social services and local health authorities, as well as voluntary, charity and private organisations, provide individual and group homes. If you wish to explore the housing options that are available, you should contact your Community Learning Disability Team.



What help can I get to help me lead life to the full?

Activities that most people take for granted – meeting people, catching a bus, having a girlfriend or boyfriend and going to the cinema – can be hard for someone who has a learning disability. Often this is quite simply because of the way society is organised. There are various projects, including befriending schemes, clubs, adult education classes, job training and specialist holidays, that can help people all over the country to lead more fulfilling lives.

Some local authorities also run adult training centres or social education centres, which aim to offer continuing education or work training, as well as providing a focal point for people with learning disabilities to meet friends. The 2001 Government White Paper also gives priority to providing jobs within the community. Since the 1980s, there has been emphasis on enabling people to take part in their communities in ways that would be valued by their non-learning-disabled peers. Such activities might include going swimming, having a paper round and going to the pub or other local amenities.

In many cases, someone's quality of life can be greatly increased by some input and advice from professionals with expertise in a specific area. Most Community Learning Disability Teams can offer speech and language therapy, occupational therapy, physiotherapy, counselling, nursing (for example, for epilepsy support), and access to psychological and psychiatric services, in addition to the practical and financial help that a social worker can provide.

Sometimes it can be difficult to get all the support you feel you need. This can depend on where you live or what level of disability you have, as well as other things. Some of the organisations listed on p. 12 can help you explore what help you are entitled to. If you feel you are not being heard, you could think about getting an advocate to help you. (See *Useful organisations*, on p. 12, and *Further reading*, on p. 14.)

Standing up for your rights

People react in different ways to those who have learning disabilities. Some are embarrassed and avoid contact, while others are over-protective and insist on helping people with things they are able to do themselves. Both attitudes are equally damaging. Some local health authorities, as well as voluntary groups, are trying to bring about a change of attitude. They are providing opportunities and support for people to become independent, to take as much responsibility for themselves as possible, and to enjoy the same rights and opportunities that most people take for granted.

In recent years, the self-advocacy movement, led by organisations such as People First, has provided opportunities for developing self-assertion and communication skills. These skills enable people to speak up for themselves and to make informed choices about what they want to do with their lives. In some cases, learning disabilities prevent people from being able to speak for themselves. Some areas offer advocacy schemes that link learning-disabled people with an independent person who can stand up for their rights and speak on their behalf (see *Useful organisations*, on p. 12, for contact details). All advocacy and self-advocacy groups are concerned with improving quality of life, opportunities and choices. They stress that it is the individual who is important and not the disability.



Useful organisations

Mind

Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: www.mind.org.uk or MindinfoLine on 0845 766 0163.

Benefits Enquiry Line

tel. 0800 88 22 00, web: www.dss.gov.uk/ba

British Institute of Learning Disabilities (BILD)

Green Street, Kidderminster, Worcestershire DY10 1JL
tel. 01562 723 010, web: www.bild.org.uk
General information, advice and resources

Citizen Advocacy Information and Training (CAIT)

Unit 162, Lee Valley Technopark, Ashley Road
London N17 9LN
tel. 020 8880 4545, web: www.citizenadvocacy.org.uk
For people wanting an advocate

Contact a Family

209–211 City Road, London EC1V 1JN
tel. 0808 808 3555, web: www.cafamily.org.uk
Help and advice for families. Parent support groups

Disability Law Service

Ground Floor, 39–45 Cavell Street, London E1 2BP
tel. 020 7791 9800, minicom: 020 7791 9801
Free, confidential legal advice

Downs Syndrome Association

Langdon Down Centre, 2a Langdon Park, Teddington
Middlesex TW11 9PS
tel. 0845 230 0372, web: www.downs-syndrome.org.uk

The Foundation for People with Learning Disabilities

83 Victoria Street, London SW1H 0HW

tel. 020 7802 0300, web: www.learningdisabilities.org.uk

General information, advice and resources

Mencap

Mencap National Centre, 123 Golden Lane, London EC1Y 0RT

tel. 020 7454 0454, web: www.mencap.org.uk

National network of support and advice services

The National Autistic Society

393 City Road, London EC1V 1NG

helpline: 0845 070 4004, web: www.nas.org.uk

Information and advice for people and families with autistic spectrum disorders

The National Society for Epilepsy

Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ

helpline: 01494 601 400, web: www.epilepsynse.org.uk

Outsiders

BCM Box, Outsiders, London WC1N 3XX

tel. 020 7354 8291, web: www.outsiders.org.uk

Self-help organisation for people who feel isolated because of social or physical disabilities

People First

3rd Floor, 299 Kentish Town Road, London NW5 2TJ

tel. 020 7485 6660, web: www.peoplefirstltd.com

Self-advocacy run by people with learning difficulties

Scope

6 Market Road, London, N7 9PW

tel. 0808 800 3333, web: www.scope.org.uk

Organisation for people with cerebral palsy

Skill: National Bureau for Students with Disabilities

Chapter House, 18–20 Crucifix Lane, London SE1 3JW

infoline: 0800 328 5050, web: www.skill.org.uk

Promoting education and training opportunities

Further reading

- The assertiveness workbook: how to express your ideas and stand up for yourself at work and in relationships* R. J. Paterson (New Harbinger Press 2000) £12.99
- The burden of sympathy: how families cope with mental illness* D. A. Karp (Oxford University Press 2001) £10.99
- Creating accepting communities: report of the Mind inquiry into social exclusion* S. Dunn (Mind 1999) £14.99
- Disabled people and mental health support services* (Mind 2003) £1
- How to assert yourself* (Mind 2003) £1
- How to cope as a carer* (Mind 2003) £1
- How to improve your mental wellbeing* (Mind 2004) £1
- How to increase your self-esteem* (Mind 2003) £1
- How to look after yourself* (Mind 2004) £1
- How to stop worrying* (Mind 2004) £1
- Keyfacts: genetics and mental health* (Mind 2001) £5.50
- Making sense of herbal remedies* (Mind 2004) £3.50
- Making sense of homeopathy* (Mind 2004) £3.50
- Making sense of traditional Chinese medicine* (Mind 2001) £3.50
- The Mental Health Act 1983: an outline guide* (Mind 2004) £1
- The Mind guide to advocacy* (Mind 2004) £1
- The Mind guide to food and mood* (Mind 2004) £1
- The Mind guide to managing stress* (Mind 2003) £1
- The Mind guide to massage* (Mind 2004) £1
- The Mind guide to relaxation* (Mind 2004) £1
- The Mind guide to spiritual practices* (Mind 2003) £1
- The Mind guide to surviving working life* (Mind 2003) £1
- The Mind guide to yoga* (Mind 2004) £1
- Mind troubleshooters: panic attacks* (Mind 2004) 50p
- Mind troubleshooters: stress* (Mind 2003) 50p
- A right result? Advocacy, justice and empowerment* R. Henderson, M. Pochin (Policy Press 2001) £16.99
- Understanding anxiety* (Mind 2003) £1
- Understanding autism in children and adolescents* (Mind 1999) £1
- Understanding depression* (Mind 2004) £1
- Understanding mental illness* (Mind 2004) £1
- Understanding talking treatments* (Mind 2002) £1

order form

For a catalogue of publications from Mind, send an A4 SAE to the address below.

If you would like to order any of the titles listed here, please photocopy or tear out these pages, and indicate in the appropriate boxes the number of each title that you require.

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Mind works for a better life for everyone with experience of mental distress

Mind does this by:

- advancing the views, needs and ambitions of people with experience of mental distress
- promoting inclusion through challenging discrimination
- influencing policy through campaigning and education
- inspiring the development of quality services which reflect expressed need and diversity
- achieving equal civil and legal rights through campaigning and education.

The values and principles which underpin Mind's work are:
autonomy, equality, knowledge, participation and respect.

For details of your nearest Mind association and of local services contact Mind's helpline, *MindinfoLine*: **0845 766 0163** Monday to Friday 9.15am to 5.15pm. Speech-impaired or Deaf enquirers can contact us on the same number (if you are using BT Textdirect, add the prefix 18001). For interpretation, *MindinfoLine* has access to 100 languages via Language Line.

Scottish Association for Mental Health tel. 0141 568 7000

Northern Ireland Association for Mental Health tel. 028 9032 8474

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