

Enable Ireland

LEARNING DISABILITY INFORMATION FOR PARENTS




A Guide for Parents of children recently diagnosed with Learning Disability or who are in the process of getting a diagnosis.



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INTRODUCTION

This booklet has been developed by Enable Ireland North East. It was born out of the realisation over many years that we did not have compact information to give to families of children recently diagnosed with a Learning Disability or who were in the process of getting a diagnosis.

We developed this booklet in consultation with families. It is our hope that it will be informative and useful to families as they learn more about their child's diagnosis.

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



WHAT IS 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'.

Learning disability used to be known as mental handicap or mental retardation. A child with a learning disability will, compared with other children of the same age, find it more difficult to learn, understand and do things. The degree of disability can vary greatly. Some children will never learn to speak and will need help looking after themselves. On the other hand the disability may be mild and the child will grow to become independent. However, even when mildly affected, it may be hard for the child to work things out and to cope with aspects of life, such as getting dressed, going shopping, or filling out forms. Others may not need very much support in their lives.

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

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 Or Autism Spectrum Disorders), there is a genetic basis for their learning disability. However, for many children the causes of their learning disability are never known.

WHAT CAUSES GENERAL LEARNING DISABILITY?

There are many possible causes of Learning Disability including genetic factors, infection before birth, brain injury at birth, brain infections or damage after birth. More specific examples include Down's Syndrome, Fragile X Syndrome and Cerebral Palsy. In nearly half the children affected, the cause of the disability remains unknown, even after all the tests have been done.




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, guidance and very practical help.

- A **Paediatrician** may see your child to assess their development and to monitor their health and progress. They can offer advice, information and support about any medical condition(s) your child may have. They may also refer your child to other specialists, for example, a Psychologist on an Early Intervention team, where their health, social and educational needs will be considered in detail.
- Some areas also have community-based **Registered Nurse for Intellectual Disability (RNID)** who can visit you at home and work closely with the family.
- **Clinical Psychologists** are health professionals who can help your child with specific problems, learning new skills and help with overcoming behaviour difficulties. 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.

- **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 with eating, drinking and swallowing.
- **Physiotherapists** can help your child with their movement. 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.

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- **Occupational Therapists (OT)** 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. The OT can also provide support in relation to accessing equipment such as specialised chairs, self care aids, beds etc.
 - **Child and Family Support Workers** can act as a link person to families and team. They can work jointly with the therapists or carry out individual sessions and groups with your child.
 - **Social Workers** work with families to help build a supportive relationship and offer practical and emotional support by providing, for example, Parent Training. Social Workers provide information around benefits and legislation. Social Workers can link you in with other services that may be relevant.

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.



GETTING A DIAGNOSIS

How & Who?

Generally, a Psychologist in conjunction with parents and sometimes other professionals (e.g. Paediatrician, Speech and Language Therapist or Occupational Therapist), will do a variety of assessments and interviews to determine that a child meets the criteria for a global intellectual disability.

This may involve formal testing where a child's learning is assessed. Learning in this case can include problem solving, reasoning, planning, academic learning and learning from experience. To assess this, the child will be asked to complete several tasks and tests with the psychologist. Those results are then measured against a group of the child's peers. It is not always possible to do formal testing, particularly if a child is very young or has complex needs.

In addition, a child's adaptive behaviour and development will be assessed and measured against his or her peers. Adaptive behaviour is a person's functioning in daily life activities, including communication, social participation, progress at school or preschool and personal independence at home or in the community. During this time a Psychologist may interview parents, ask them to complete questionnaires and may also visit a preschool or the home to assess how the child is progressing.

Once the assessment is completed a Psychologist will provide a report with all the results, a conclusion and recommendations. This will indicate your child's current level of functioning. This can also explain what their strengths and weaknesses are and how best to support them. An overall score may indicate that they fall into a particular category of intellectual ability – Mild, Moderate, Severe, Profound. A profile where a child has big differences between their strengths and weaknesses may mean it is not possible to give an overall score. The assessing Psychologist will be able to discuss questions you might have about your child's results.

Given that children develop and progress at different rates it is often useful to have your child reassessed after 18 months to 2 years. This will ensure that they continue to be supported appropriately. An assessment can be accessed through **NEPS** (Psychologists employed by the Department of Education who service schools in Ireland), Enable Ireland or the 6-18 Children's Services Disability Team.



What does an assessment of learning disability mean for my child's future?

This is a very difficult question to answer and particularly for children under six years it is unwise to predict too far in advance. As with all children they develop at different paces and have different strengths, needs, interests, fears and hopes. Therapists and doctors may be able to assist with explaining what their specific needs are and how they may progress but, given the many different factors involved, will be cautious in saying how the future might turn out. It is important to remember that learning is just one part of your child's development and that all children need support, love and guidance to develop to their potential.

SCHOOL OPTIONS AND SUPPORT

If your child has been diagnosed with a Learning Disability it may be useful to think about the following in relation to schools:

Choosing a school

Choosing a school for your child is a big decision for any parent. There are a number of schools in counties Meath, Cavan and Monaghan that cater for children with differing levels of ability. It may be useful to link with your keyworker or local **Special Educational Needs Organiser** (SENO) to discuss which school might best fit your child's needs. Visiting the school and meeting the principal and teachers can help you make a well informed decision.

Support in school

It will be useful for the class teacher to know about your child's learning profile. Passing on and discussing any recent reports and their personal strengths and weaknesses will allow the teacher a better understanding of your child. It can also be helpful to discuss a specific set of educational or social goals that your child will work towards in the school year. This can be done in an **Individual Education Plan** (IEP) with the teacher.

Your child may also be entitled to resource hours (one-to-one support outside the classroom), learning support (in a smaller group) or a Special Needs Assistant in the class. Applications for these are done through the school and are sanctioned by the SENO. Generally a report will be required from a professional (e.g. General Practitioner, Occupational Therapist, Speech & Language Therapist, Psychologist, etc) recommending these.

The National Council for Special Education (NCSE) provide a useful information booklet for parents as well as information on their website. Details are given at the end of this booklet.



HELPING YOUR CHILDREN AT HOME - BEHAVIOUR

Some children have behaviours that parents find very difficult to manage, and that cause considerable stress for the whole family. Before you try to tackle behaviour, decide whether it really is a problem rather than just inconvenient or embarrassing. It is always useful to start by trying to identify the reason for the behaviour from the child's perspective, and considering what the child is trying to communicate through their behaviour. Some behaviours are directly linked to difficulties the child has communicating because of their Learning Disability. Other triggers might be social situations which they find stressful, unstructured time, sensory difficulties, medical reasons, and change which your child finds stressful. You may find it helpful to track your child's behaviour in a diary so you can begin to see patterns in behaviour and notice small, positive changes as you develop strategies. Understanding your child's particular difficulties will help you develop strategies to help with behaviour problems. Try to be consistent when dealing with difficult behaviour, and don't expect it to change overnight.

Exercise, such as trampolining or swimming, can be a really good way of relieving stress and working-off frustration.

Sometimes a member of our team can give practical advice, or it may help to talk to other parents who have experienced similar problems and who have developed creative solutions to help their child. There are several helpful books giving advice on strategies for difficult behaviours. Details are given at the end of this booklet.



BROTHERS & SISTERS OF A CHILD WITH LEARNING DISABILITY

When a child is diagnosed with Learning Disability it affects the whole family and it is important to consider the feelings of siblings and to recognise that they have a need for information about their brother or sister and what Learning Disability means for them. They need information for reassurance, to answer their own questions and questions posed by others, and to plan for their future. This need is lifelong and the topics are ever-changing. Throughout their lives, the types of information siblings need – as well as how it is best presented – will vary with the sibling's age.

Brothers and sisters may have feelings that are difficult to express, even to a friend; sadness that a sister can't learn things that others take for granted, anger when a brother's behaviour problems prevent the family from doing things other families do, or the special pride when a sibling with a disability learns a basic but important life skill after months or years of practice.

Members of your team and other parents can help you work out the type of information your other child or children need, as well as how best to give them that information. 'Sibshops' may be available – these are fun workshops where siblings can meet with others in a similar position in a positive environment to learn about learning disability and other disabilities, share experiences and feel that others understand them.



BUILDING SELF-ESTEEM AND CONFIDENCE

Here are some key things that parents can do to help:

- Be empathetic. See the world through your children's eyes.
- Communicate with respect. Don't interrupt or put them down; answer their questions.
- Give undivided attention - children feel loved when we spend one-on-one time with them.
- Accept and love children for who they are. This will allow them to feel more secure in reaching out to others and learning how to solve problems.
- Give children a chance to contribute. This communicates your faith in their abilities and gives them a sense of responsibility.
- Treat mistakes as learning experiences. Children whose parents overreact to mistakes, tend to avoid taking risks and then end up blaming others for their problems.
- Emphasise their strengths. A sense of accomplishment and pride gives children the confidence to persevere when they face challenges.
- Let them solve problems and make decisions. Avoid telling children what to do; encourage them to come up with solutions to problems.
- Discipline to teach. Do not discipline in a way that intimidates or humiliates your child.

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 help available from support groups and other organisations like Inclusion Ireland, Enable Ireland, Federation of Voluntary Bodies, your child's school and the HSE.



BENEFITS AND ENTITLEMENTS

Applying for benefits can be difficult for parents as it often means describing your child's difficulties rather than his or her strengths. The language used on many forms can be upsetting and outdated. It can also be a time when you realise how much help and support your child actually needs. Many families also question whether they are eligible to claim certain benefits, believing they are for needier families. It is important to remember that your child has a right to apply.

An up to date information booklet regarding 'Benefits & Entitlements' is available in the Enable Ireland Centre. A team member will be able to advise you further.



GLOSSARY

A note on terminology:

The term *learning disability* is a label. It is convenient in discussion and for planning services. But people who carry that label, wear many others, such as *friend, neighbour, relative, employee, colleague, fellow citizen*. A label describes one aspect of a person, but does not capture the whole person. Many people with learning disabilities prefer the term *learning difficulties*. This is the wording used by People First, an international advocacy organisation. In the UK, the Warnock Committee has suggested that learning difficulties should be used to refer to specific problems with learning in children that might arise as a result of issues such as medical problems, emotional problems, and language impairments. Learning disabilities can be a useful term in that it indicates an overall impairment of intellect and function. Alternative expressions are also used, for example *developmental disabilities* and *intellectual disabilities*. There is at present no clear consensus. It is however widely accepted that whatever terms are used they should be clear, inclusive, and positive.

Learning disability is different from the term ‘specific learning disability’, which means that the person finds one particular thing hard but manages in everything else. For example, a child can have a specific learning difficulty in reading, writing or understanding what is said to them, but has no problems in other areas of life. Like all children, children with learning disabilities continue to progress and learn throughout their childhood – but more slowly. Disability does not stop a child from having a full and enjoyable life. If your child has a learning disability, there is a great deal that can be done to help them achieve and lead a fulfilling and valued life.

Learning disability is a diagnosis, but it is not a disease, nor is it a physical or mental illness. Unlike the latter, so far as we know it is not treatable. Internationally three criteria are regarded as requiring to be met before learning disabilities can be identified:

1. Intellectual impairment
2. Social or adaptive dysfunction
3. Early onset

1. Intellectual Impairment

IQ is one way of classifying learning disability. Four labels are used to describe the levels of functioning.

- 50-70 mild learning disability
- 35-50 moderate learning disability
- 20-35 severe learning disability
- Below 20 profound learning disability

However, there are problems with using IQ alone. Measurements can vary during a person's growth and development, particularly in childhood. Also, many of us have individual strengths and abilities which do not show up well in IQ tests. It is important to also take into account the degree of social functioning and adaptation.

2. Social or adaptive dysfunction

Measuring the degree of impairment or social functioning can be difficult. Social and adaptive dysfunction considers day to day activities such as relating to others, communicating, eating and drinking, toileting and gross and fine motor skills (e.g. pencil grip, walking and balance).

3. Early onset

The third criteria is that these impairments can be identified in the developmental period of life. They are present from childhood, not acquired later as a result of an accident, adult disease or illness, or dementia.



A **global learning disability** indicates significant limitations in at least two areas of adaptive functioning and intellectual functioning.

A diagnosis of **global developmental delay** means that a child is too young to assess with formal testing, but has displayed sufficient signs to indicate concerns with a number of areas of development. This is generally given to children under five years.

Specific learning disabilities (e.g. **dyslexia** or **dyscalculia**) can be diagnosed when a person with average intelligence has a specific area of difficulty or need (e.g. reading or writing).

Educational assessment – is an assessment of the nature and extent of the child’s learning ability sometimes with recommendations for school placement or access to support (e.g. resource hours).

Learning support - is designed to help children with learning difficulties to achieve success at school. This is generally done by allowing smaller groups of children (usually between 3-5) to go out of class for between 30mins to an hour with a resource teacher and focus on particular needs. Schools are able to identify which children might benefit from learning support.

Resource hours – enable children with specific needs to benefit from one to one teaching with a resource teacher. These are allocated to particular children based on guidelines set out by the Department of Education (special education circular 02/05). They are applied for by the school and generally require an accompanying report from professionals identifying specific needs.

Special Education Needs Organiser (S.E.N.O.) - A SENO works for the National Council for Special Education (NCSE) and is an important link between the school and the Council. SENOs are involved in granting SNAs and resource hours to children. The contact details for your local SENO can be found at http://www.ncse.ie/contact_us/SENO_List.asp

Special Needs Assistants (SNAs) are recruited to assist in the care of pupils with disabilities in an educational context. They can be appointed to a special or mainstream school to assist that school in making suitable provision for a pupil with special care needs arising from a disability. SNAs may be allocated on a full or part time basis, and may be shared between named pupils for whom such support has been allocated (Department of Education Circular SP.ED 07/02).



The criteria for allocation of an SNA include

- significant medical needs for assistance
- significant impairment of a physical or sensory function
- behaviour which means the child is a danger to themselves or others

When applying for a Special Needs Assistant for a pupil, professional assessment and diagnosis of the child's care needs is required, outlined in a report which describes the child's special care need and gives a signed recommendation from the professional that the support of a SNA is necessary, and to what extent (full time, part time, mornings only, etc.). The decision made by the SENO regarding SNA support for a child can be appealed to the NCSE by the school and parents, provided new relevant information is submitted that was not included with the original application.

Individual education Plan (IEP) - The Individual Education Plan is developed through a collaborative process involving the school, parents, the student (where appropriate) and other relevant personnel and agencies. It refers to the adapted or modified aspects of the educational programme and focuses on priority learning needs, although the student may also have other learning needs that will not require the same degree of planning and monitoring. Not every aspect of the curriculum and school life needs to be modified for every student with special education needs – only those areas of identified need arising from assessment should be covered. The amount of adaptation and support will vary according to the individual learning needs of each student. Some students with more complex needs may require significant educational modifications.

Special schools – these are schools catering for children with specific learning or physical needs. These schools generally require specific needs to be identified before a child can attend. Specific schools in your area can be found on the website www.ncse.ie. Click on the 'For Parents' tab and then on 'Special Classes' for an up to date list.



NATIONAL ORGANISATIONS & AGENCIES

Enable Ireland

Enable Ireland's mission is to work in partnership with those who use our services to achieve maximum independence, choice and inclusion in their communities

Down Syndrome Ireland (DSI)

DSI is dedicated to being the primary source of information and support to people with Down syndrome, their families and the professional community.

Share the Journey

Supporting Parents of Deaf and hard of hearing children, 0879163168 or 0857225659

Health Service Executive

The HSE delivers thousands of different health and social services in hospitals and communities across Ireland

Department of Education and Science

National Federation of voluntary Bodies

services to people with Intellectual Disability

Inclusion Ireland

Inclusion Ireland provides an information and advice service to people with an intellectual disability, and to their families

National Council for Special Education

Working to deliver a better special education service

The Jack and Jill foundation

Supports families of children who suffer severe intellectual and physical developmental delay.

LAMH

Lámh is a manual sign system used by children and adults with intellectual disability and communication needs in Ireland.

Carers Association

This is a national voluntary organisation “for and of family carers in the home. Family carers provide high levels of care to a range of people including older people, people with severe disabilities, the terminally ill and children with special needs”.

Neurological Alliance of Ireland

NAI is an umbrella organisation for groups representing the views and concerns affecting those with neurological conditions

Barnardos

Barnardos’ vision and mission are to make Ireland the best place in the world to be a child and a place where all children are cherished equally. Barnardos provide bereavement counselling for children

Gingerbread

Gingerbread Ireland is the National Association for One-Parent Families

Make a Wish Foundation

Make-A-Wish® has one simple aim - We grant the wishes of children aged between 3 and 17 years living with a life-threatening medical conditions to enrich the human experience with hope, strength and joy

Contact a Family

Contact a Family is UK based charity that exists to support the families of disabled children whatever their condition or disability. Families can access the **CaF directory** of specific conditions and rare disorders.

Irish Cancer Society

The Irish Cancer Society is the national cancer charity for support, nursing, research, fundraising & advocacy.



BOOKS

The Essential Guide to Special Education in Ireland

Dr. David Carey

Parenting Preschoolers and Young Children

John Sharry, Grainne Hampson, Mary Fanning, Mater Misericordiae Hospital, Dublin

Positive Parenting: Bringing up responsible, well-behaved and happy children

John Sharry, Mater Misericordiae Hospital, Dublin

We can do it! Helping children who have learning disabilities with bowel and bladder management: a guide for parents

Enuresis resource and information centre (2002)

Sleep Better! A guide to improving sleep for children with special needs

V. Mark Durand

Paul H. Brookles (1998)

Focussing on Peers: The importance of Relationships in the Early Years

Donna S. Wittmer (2008)

Getting in Tune: The Powerful Influence of Music on Young Children's Development

Levine-Gelb Communications, Claire Lerner, and Lynette A. Ciervo (2002)

Power of Play, The

Claire Lerner & Sharon Greenip (2004)

The New Language of Toys

Schwartz, S & Heller Miller, J.E. (1996)

Hanen It Takes Two to Talk

Pepper, J & Weitzman, E (2004)

Baby Talk: Maximise your Child's potential in just 30 minutes a day.

Ward, S. (2004)

The Out of Sync Child

Kranowitz, C.S.

Thinking in pictures

Temple Grandin (1996)



BOOKS TO READ WITH CHILDREN:

Giraffes Can't Dance (by Giles Andreae)

Gerald would love to join in with the other animals at the Jungle Dance, but everyone knows that giraffes can't dance ...or can they? A funny, touching and triumphant story from an award-winning creative team.

Small Knight and George (by Ronda Armitage)

Knights are supposed to be big, brave dragon fighters, but Small Knight doesn't feel big or brave. In fact, he shivers in his boots as he rides out on his horse in search of a fierce dragon. He goes from place to place, asking the local people if they've seen a dragon that he can fight, but he is always a little too late. A fierce dragon has already come and then gone from each place he visits. The people tell him frightening dragon stories, which makes Small Knight realize that he really doesn't want to fight a dragon at all. On his way home at the end of the day, Small Knight meets a strange but friendly little creature hiding in the shrubbery. What Small Knight fails to realize is that this friendly meeting will cause general panic the moment he returns home to his castle.

Barry The Fish with Fingers (by Sue Hendra)

Life under the sea can be as dull as dishwater, until Barry arrives, that is. See, Barry is no ordinary fish—he's a fish with *fingers*! And fingers mean finger puppets, finger painting, knitting, counting to ten, tickling, and all sorts of fun things. It isn't long before all of the other fish want fingers, too. Life under the sea will never be the same again....

Elmer (by David McKee)

Elmer the elephant is bright-coloured patchwork all over. No wonder the other elephants laugh at him! If he were ordinary elephant colour, the others might stop laughing. That would make Elmer feel better, wouldn't it? The surprising conclusion of David McKee's comical fable is a celebration of individuality and the power of laughter.

Marvin Gets MAD! (by Joseph Theobald)

One perfect morning Molly eats the very apple that Marvin had his eye on. This makes Marvin MAD. Who will be able to calm Marvin down and tease him out of his tantrum? Will he be able to do it by himself or will he need some help?

USEFUL WEBSITES

These websites are not under the control of Enable Ireland and therefore Enable Ireland is not responsible for the availability or content of these external sites, nor does it endorse, warrant, or guarantee the products, services, views or information described or offered at these other Internet sites.

http://www.ncse.ie/publications/Parental_Booklet.asp

Information booklet for parents of children with special educational needs, published by the National Council for Special Education. It aims to provide information on the full range of educational supports available in schools for children with special educational needs.

Published in October 2011.

www.inclusionireland.ie

The Vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential.

www.citizensinformationboard.ie/publications/entitlements/downloads/children_with_disabilities.pdf

Provides information about entitlements for children with a disability

www.idaal.com

idaal.com is a consortium of Intellectual Disability Libraries established to provide easy and comprehensive access to up-to-date information in this and related fields thereby supporting research, best practice and education in our services.

www.nclid.org

National Centre for Learning Disabilities

www.leap@ireland.com

Leading, Educating, Advocating and Planning, LD and ASD Ireland

www.zerotothree.org

Promoting the health and development of infants and toddlers.



www.earlychildhoodireland.ie

Early Childhood Ireland is a national member based organisation for early childhood care and education providers in Ireland. Information on various schemes (e.g. ECCE) and options available to support young children's early education in Ireland.

www.childcare.ie

Information base for finding your County's local Childcare Committee.

www.eric.org.uk

ERIC is the UK's only childhood continence charity. We work to improve the quality of life of children, young people and their families in the UK who suffer from the consequences of childhood continence and to assist them to manage or overcome these problems.

www.solutiontalk.ie

Parenting support

www.claphandies.com

Service that offers PlayLabs, First Aid training and Baby Massage

www.thesanctuary.ie

Health and well being courses and workshops

GENERAL PARENTING WEBSITES:

www.rollerocaster.ie

www.magicmum.ie

www.mykidstime.ie



OTHER RESOURCES

www.thinkingtoys.ie

access to therapy products from Irish owned company

www.do2learn.com

This website provides information on teacher and parent material, educational supplies, games and resources for children with special needs.

www.offwego.ie

Parent's website focusing on books and materials for children with special needs.

www.sparklebox.co.uk/ireland/

Useful website for finding resources and materials for children with special needs.

www.notimeforflashcards.com

Site dedicated to Learning and Play for Babies, Toddlers and Kids

www.Helpkidzlearn.com

Fun, accessible games & activities designed specifically for young children & those with learning difficulties.

Enable Ireland

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