Finding out about...

Services for children with disabilities and their families



A guide for parents and carers





Contents

Introduction	3
The early years	6
Going to school	8
Local authority services	
for children and families	16
Play and leisure	21
Who does what – an A-Z	24
Sources of further information	31

This booklet has been developed by the ENABLE Scotland Information Service and by the ENABLE Scotland Children's Committee — a group of parents of children with learning disabilities — to let you know that others understand your difficulties and joys and to put you in touch with the services and support that you and your child needs.

This booklet is for general guidance and is not intended to be a definitive statement of the law.

Introduction

There are a number of community services that can provide support to you and your family. You may not need all of these but it can be important to know what services exist, what each does and what rights you and your child have to services.

Sometimes getting access to a service is simply a matter of asking or applying to the right person. At other times, your child may need to undergo an assessment by an agency or a range of professional staff in order to identify your child's needs and the best way in which each agency or professional can help.



Assessments and plans

Assessments can open the door to services. Often, it simply means talking to staff from health or education or social work. At other times, it may mean that your child takes part in some tests — for example



to check how they are learning or developing. This might mean that the relevant professional will observe your child at home or at school doing certain tasks.

The local authority

has to look at the needs of all the people that live in its area and is allowed to take cost into account so you won't always get everything you need. But if you can be as clear and specific as possible about the needs of you and your child then you stand a better chance of getting appropriate support. An assessment should lead to a plan that gives details of what service or support is going to be arranged. You can check that the plan reflects the things that were discussed during the assessment. If not, you may be able to ask for a review or complain and get things changed.

It is possible that your child may need to have a number of different assessments and these are outlined in this booklet. Each may lead to a plan.

How children's services are changing

Children and their families have traditionally been helped by different parts of the local authority or through different agencies — each with their own systems and ways of doing things. This has not always led to the best outcomes for children and has sometimes meant that families had to knock on the doors of different agencies and explain their situation again and again.

"Every time I went, I saw a different person and had to go over my son's problems from the start. Why don't professionals read the files or share information?"

Now the government has a new national programme for all children called *Getting it right for every child.* This is changing the way that organisations think and act to help children and their families. Increasingly, agencies and government departments - like social work, education and health - work together, share information and offer integrated services. This should make it easier for a child to get the support that he or she needs and be linked into the right agency to provide it. In future a child may have only one plan.

The early years



The early years and pre-school period of a child's life are important opportunities for a child's learning and development. Playgroups and nurseries are pre-school experiences available to all children. Nurseries are provided by the local authority or by private business. All children aged

3 years and over should be able to have a nursery place in their local community. Your local authority children's services department can provide you with information on playgroups and nurseries in your area.

'Because of his speech my son was referred to a child assessment centre run by the Health Board. The physiotherapist was also concerned about his mobility. At the assessment centre all the therapists were able to assess him. While he was there they had a joint meeting and decided he should continue to attend the centre. We were also introduced to home visitors and they came to our home to give us support. When my son was three and a half he started to attend a local nursery and was introduced to an educational psychologist. We had an auxiliary at the nursery for the two years before my son went to school.'

Getting help early

Playgroup and nursery staff are often experienced childcare workers who are trained in child development. They can recognise if a child would benefit from additional support in some aspect of

their development. The nursery staff will discuss their thoughts with you and, if appropriate, will contact the local authority educational psychologist for advice and support for your child. As a parent you may think that your child would benefit from additional support in the nursery and you can approach the nursery staff directly or talk to your health visitor or GP.

Your local authority education department must provide appropriate additional support for disabled children under 3 (or under 5 if not in a public or partnership nursery), where the child has been referred by a health authority and has additional support needs.

Different local authority areas have different systems for co-ordinating services provided to children with disabilities e.g. Professional Advisory Group, or Multi-disciplinary Team, or Pre-School Assessment Team (PRE-SCAT), or Early Years Community Assessment Team. It may be called something different in your area. A referral to such a group for your child will generally come from your health visitor or home visiting teacher or psychologist.

Remember

It is important to get the right input at the beginning. All children have the right to reach their full potential. Professionals are there to support you and your child and help you get the appropriate services that will provide additional support for your child.

Going to school

Going to school is a big step in any child's life. If your child finds it difficult to learn he or she may already be known to the educational psychology team in your local authority education department. The team will work with you to recommend the best school for your child and the best ways of supporting your child at school.

If there is a range of schools in your area you will need to decide which school will best meet your child's needs. Previously, many children with disabilities were educated in special schools. Now the policy is to educate children in their local schools as far as possible. This means that the local authority education department will want to consider first if the local school can meet your child's needs - possibly with some extra classroom support. This is not always suitable for all children and sometimes a special school can be the best option.

"It was hard deciding on the right school for my daughter. I wanted her to go the local school like her sister but I wasn't sure if she would cope. But the head teacher was very encouraging and it's worked out fine."

Some parents and children prefer the local school as it offers the chance for disabled and non-disabled children to learn together, to share the same curriculum and activities and for natural friendships to develop. Other children and their parents prefer the smaller classes, specialised teaching and more sheltered environment offered by special schools.

Choosing a school

You have a right to request a place at the school of your choice and the local authority must grant this request if possible. However, the local authority can refuse your request for various reasons. It is allowed to consider things like -

- the cost of employing extra staff or creating extra classrooms
- whether the school is suitable for your child's age, ability or aptitude
- whether providing for your child in the school would be at the expense of other pupils' education
- whether the school is for children with additional needs and the local authority thinks your child does not need the equipment or specialist staff there.

Most schools have a catchment area and most children go to their local school. You can enrol your child on the advertised date. If you want your child to go to another local authority school then you will need to make a formal placing request in writing to your local authority. It is usually helpful to check first if the school of your choice is able to offer your child a place. If the local authority turns down your placing request then you have a right of appeal.

"The educational psychologist helped me to choose James' school. We went round all the schools and took James as well. It wasn't my first choice but I liked what I saw."

For more information on choosing a school, get a copy of *Choosing a school.* (See section 7).

Personal learning planning

All children at school are expected to take part in personal learning planning. This involves a conversation with the child about their targets for learning and development. There will be some kind

of record of the targets and the child's achievements. This has no set format and each school will have its own way that it records this and how it shares the information with parents and involves them in the process.



Extra measures for some children

Some children have significant learning difficulties that may need special measures and ongoing review. Special

measures can include an adapted curriculum, communication equipment, therapy services or extra support in the classroom. Teachers and education staff continually assess children to ensure that they are achieving what is expected at any stage. If

"The speech therapist arranged a programme for the teacher to do with my daughter at school. We also practise this at home with her."

a child is not progressing as well as the other children in the class, the teacher will first look at what can be done within the classroom. The teacher can adapt what is being taught and how it is being taught, or remove distractions and create a more appropriate learning experience for the child. If appropriate, the school will ask for the assessment and advice of the educational psychologist or other specialists such as the speech and language therapist.

Under the Education (Additional Support for Learning) (Scotland) Act 2004, the local education authority must make "adequate and efficient" provision for young people who need extra help at school for any reason. These children are said to have additional support needs. Your local education authority must take these into account when providing education for them in their own schools - or elsewhere if the education authority has placed a child outwith its area.

Individualised Educational Programme

Some children with additional support needs will have an Individualised Educational Programme (IEP). This is a short plan outlining the next steps that will be taken to help a pupil achieve a specific curriculum goal. The steps may be quite small but will be very focused on helping the child to make progress in some area of learning. The IEP should be reviewed and updated regularly by the school.

Co-ordinated support plan

Some children will have support needs that are significant, multiple or complex. If those needs will last a year or more and will require significant additional support from more than one agency, then the child

may be eligible for a coordinated support plan. It replaces the old record of needs.

The co-ordinated support plan is a formal document and it can be helpful, but remember your child has a right to proper educational support, whether or not he or she has a co-ordinated support plan.



A co-ordinated support plan covers:

- Why your child has additional support needs.
- Your child's educational needs.
- The additional support that is required.
- Your child's skills and strengths.
- Who will provide the support.
- Who will be responsible for arranging the support.
- The school that your child attends.
- Details of the person you can contact to find out about the plan.
- Contact details and the preferred method of communication of the young person in the plan and his or her parents or guardians.
- A statement by the young person in the plan. (optional)
- A review timetable.

To get a co-ordinated support plan your child needs a formal assessment. You can write and ask the local education authority to carry out an assessment to see if a co-ordinated support plan is needed, or the school can ask for one. If you want to make sure that your child is seen as part of this assessment, then ask for a psychological examination. The local authority must investigate (unless it would be unreasonable to do so) and decide whether the child or young person has additional support needs and whether they need a co-ordinated support plan.

They must tell you whether they will do this within 4 weeks of receiving your letter. They then have another 16 weeks to gather relevant information and provide you with a plan or tell you why they believe that the young person does not need one. This can be extended to 24 weeks where schools are on holiday or for some other reasonable delay. If you are unhappy with a decision about a co-ordinated support plan, you may be able to appeal to an Additional Support Needs Tribunal.

If you want further information, contact your local authority education department or Enquire, the Scottish advice service for additional support for learning (see section 7).



Extra resources in the classroom or school

Where there are children with extra support needs in a school, the local authority may give extra resources to the school, e.g. classroom assistants or auxiliaries. Sometimes these resources are allocated to individual children, e.g. where a child may need an assistant to take notes or scribe for him or her. Often, however, these resources are given to the school in order to boost the staff/pupil ratio and ensure that all children have their needs met. So, sometimes, the classroom assistant or auxiliary will be a more general source of help to the teacher.

Support at meetings

If your child is having difficulties at school you may find yourself attending various meetings to discuss his or her progress with the head teacher and other staff. Many parents can find this stressful. You should be able to take along someone else for support. Your 'supporter' can help you by taking notes so you don't have to worry about remembering everything or can remind you about questions you wanted to ask or points you wanted to get across. It can be reassuring to have someone who can help you prepare your thoughts in advance or go over things with you afterwards.

"I don't know what happened. All these people were talking about my child. I couldn't think what to say until the meeting was over and I was on my way home."

Think about asking a friend, relative or another parent to go with you to meetings.

Local authority services for children and families

Your local authority has responsibilities towards children and their families. For children with disabilities it must aim to minimise the effects of disability on them and their families, for example by arranging for 'respite care' or 'home care' to give you a break. It employs occupational therapists who can help with aids and adaptations to your home if this is necessary.

Traditionally, support to families was arranged through the social work department but recently local authorities tend to have merged many of the previous departmental boundaries so that they are able to provide a more unified service. Many local authorities will have a Children and Families department or it may be linked with the Education Department or part of a wider Community Services Department

To obtain relevant services you should find out which part of your local authority deals with children's services and ask them to assess both you and your child. A social worker or occupational therapist will then call on you to identify what help you might need and what can be done to support you. There are two assessments available though they may both be carried out at the same time. Don't just ask for one

 ask for them both as they build upon each other and will lead to a better picture of your needs being established.

The local authority must assess children and carers if it is asked to do so. This is the law. The assessment process is very important and can open the door to resources. It can assist you to obtain:

- some services
- direct payments (money) so you can buy services or employ staff
- funding
- referrals to other agencies who might be able to help
- support when you don't know where else to go
- information.



Children's assessment

Any child affected by disability is entitled to a children's assessment under Section 23(3) of the Children (Scotland) Act 1995. This means your child with disabilities but also his or her brothers and sisters. It also includes children whose parents are disabled. The assessment will be used to develop a care plan that clearly identifies the resources required to support a young person who is disabled or affected by disability in his or her family.

You can ask the local authority to assess your child. Carers, parents and the child can receive a copy of the completed assessment as well as any care plan.

> "Before I had the assessment, I didn't realise that I needed to think about the rest of my children and how my daughter's disability was affecting them."

Carer's assessment

You are a carer if you look after a relative, partner or friend who needs support because of age, disability or illness. It includes parents who are caring for a child or adult son or daughter. You have a right to ask for an individual assessment to discuss what help you need to continue in your caring role.

A carer's assessment will cover:

- what help is needed by the child or adult you care for
- what help you provide at the moment
- how being a carer affects your life
- your ability and willingness to continue providing care
- what kind of services and support are available that might help you continue in your caring role.

The local authority should take this into account when deciding what services you and your child needs. However, there is no legal duty at the moment to actually provide services to carers.



Preparing for assessments

Try to be prepared for an assessment so you are really clear about what you and your child need and can ask for this. Make sure you have thought about how your child's disability affects him or her and the rest of the family — including the impact that it has had on your own life. It can be hard to do this but the worker who does the assessment needs to build a picture of your needs. He or she may need to take that information back to their agency so a more senior manager can make the decision about what resources you might get. The more you can contribute to the assessment, the more helpful this will be.

Don't be reluctant to ask for help

Parents are often reluctant to contact the children's services department. For many it remains a stigma to have social work involved. Some resources, however, are only available through the local authority. Therefore, it is important to try and overcome any reluctance and use the services

"I didn't envisage having all these problems. I thought I would treat him like a normal wee boy - but he has extra needs". available to support you and your family and improve your quality of life. Contact with other parents or support groups can reassure you that many other parents have made contact with the local authority and had assessments.

Sometimes you may have to do your own research about what is

available to you. The Information Service at ENABLE Scotland can help you with this.



Play and leisure

All children enjoy playing and joining in leisure activities. Children need these experiences for lots of reasons. It helps children develop their understandings and they learn to mix and make friends with other children in lots of different places - playgroups, nurseries, crèche facilities and in the park.

There are many facilities in your local community that provide opportunities for play and leisure for children. Many children with additional support needs use their local playgroups and nursery schools. Some groups are more experienced than others in including children with additional support needs. Your child has the right to have a place in your local provision.

"I just feel that it's so important to keep her in touch with other children"

School-age children with additional needs should be able to join in local community resources and access local facilities. These facilities should be accessible for all children. Some areas have special summer play-schemes and other activities for children with additional support needs. Your local authority should be able to tell you about these.

All children need play and fun. If you need information on play and places to go with your child, contact your local childcare partnership. Every local authority has a childcare partnership.

There might be a support group in your area for children with additional support needs and

"The Tuesday group let me meet other parents and the children played with each other. We both got something out of it". their families. This can provide a great source of encouragement and information from other parents in a similar situation to you.

Projects that support families and children to access play and leisure can help your child to feel part of things. It is good for your child to have time to play with his or her own friends. There are also some projects just for brothers or sisters of disabled children

"My child needs something that's just for him away from his brothers and sisters".

Leisure time can bring its own difficulties. Your child might feel sad that he or she cannot keep up physically with the other children. Your child might feel that the other children don't want him or her to play because he or she is slow.

'My child doesn't want people to see his splints.'

Persevere, sometimes things just take time. Other children might not understand your child's difficulties but if children play together and go to local clubs and activities, they will learn about each other. For children to develop socially and emotionally, play is an important aspect of their daily life. Mixing with peers can help a child feel independent and develop confidence and skills.

Go to play groups and other facilities in your area and see what's available. The local social work department and childcare partnerships should have lists of groups in your area. If there isn't a group, start your own!

"It is so important for children to mix with other children at an early age".

Childcare Partnerships

The telephone numbers and contact details can be found in the telephone book or by contacting your local council. Try your local council website. Information about childcare services in your area can also be found at www.childcarelink.gov.uk/.



Who does what – an A-Z

Here are some of the professionals that you and your child may meet.



Who's who in health services

These are usually accessed through your family doctor and health visitor. After that, the first step is often an assessment by a paediatrician and, if necessary, other health care professionals.

Sometimes your child may be referred to a child development centre for assessment. These centres will have a team of staff, which can include Community Paediatricians, Specialist Health Visitors, Occupational Therapists, Physiotherapists and Speech and Language Therapists. Often centres also run support groups for parents and carers.

Clinical Psychologist – can provide diagnostic, therapeutic and counselling services to a child who is experiencing emotional, thinking, learning and social difficulties. A Clinical Psychologist is employed by the Health Service. A referral is made through your GP. They are different from an Educational Psychologist.

Community Learning Disability Nurse

– can provide assessments and support. They work closely with school nurses, teachers, and educational psychologists. They most often work with adults.

Dietician – can provide support for infants and children requiring dietary advice e.g. food intolerances and allergies, tube feeding, diabetes.

General Practitioner – the general practitioner or doctor is the first point of contact for most medical services. They provide a complete spectrum of primary health care within the local community. The GP has an extensive knowledge of medical conditions and will assess a problem and decide on a course of action. Where necessary, your GP will refer your child to specialist health services.

Health Visitor — a qualified nurse who promotes health within a GP practice. They have specialised training and are experienced in child health, health promotion and health education. They help people to stay well and avoid illness. They are there to listen and to help, advise and support in all situations. A health visitor is often the first person to spot that a child is having difficulties and can help in getting access to early services.

Occupational Therapist – can assess a child's sensory and motor skills and provide therapy programmes that can be carried out at school and home. These activities are aimed at improving the child's sensory motor development and support them to be more independent in their daily lives.

Paediatricians – these are doctors who specialise in children and their development. They can give full medical assessments and provide investigations, which may lead to a specific medical diagnosis.

PRE-SCAT team (Pre-School Community Assessment Team) – a team of professionals who help co-ordinate services for your child. They plan for the future and keep a register of children to ensure that their needs are reviewed. Not all children with additional support needs are referred to PRE-SCAT. Not all areas have this service or it may be called something different in your area.

Physiotherapist – assesses and treats your child in relation to their physical movement. They can provide you with a variety of play and exercise programmes that support your child to become more independent. If required, the physiotherapist may provide special equipment.

Speech and Language Therapist – can assess and diagnose your child's communication. They develop programmes to support your child's communication development. They can also support children with swallowing, eating and drinking.

Who's who in educational services

These are usually accessed through your Local Authority Education Department. The Education Department will provide you with information leaflets and a list of local resources - playgroups, nursery schools and schools, for pre-school children and school age children.



Careers Officer – can advise you and your child on options available on leaving school - such as life-long learning and job opportunities.

Classroom Assistant – helps the classroom teacher with tasks in the classroom. They are not specifically employed to support children with additional support for learning but to assist the teacher in more general ways.

Classroom Teacher – organises the class lessons and works with the children to enable them to learn. The class teacher may be the first person at school to identify your child's additional support for learning. They will also be the person that you can talk to about any concerns you have about your child's learning.

Educational Psychologist – assesses your child's progress. They usually become involved with your child if the school makes a request to Education Psychological Services for support. They can provide help and advice to families and school staff on accessing the curriculum, social, emotional and behavioural support.

Guidance Teacher —co-ordinates personal support for pupils. All pupils must have someone in the school that they can talk to in confidence about anything that is bothering them. The Principal Teacher for Guidance is also responsible for personal and social development (PSE) in the school which covers topics like relationships, health education, career education and personal planning.

Head Teacher – responsible for the management of the school. The head teacher allocates human resources to support children's learning. He or she often co-ordinates and chairs reviews and gathers together the views of those within the school involved in your child's education. He or she will also deal with any concerns you may have that the classroom teacher cannot resolve.

Learning Support Teacher – advises other members of staff about resources, methods and strategies to assist your child to access the curriculum. Or they may provide a teaching opportunity in small groups for children or they may provide training for other staff.



Nursery Nurse – supports your child to access learning through play at a nursery or a playgroup.

Pre-School Home Visiting Teacher – teachers who visit your home and support your child to learn and develop before he or she goes to school. Not all areas have this service.

School Nurses - are involved with health promotion and education, prevention of ill health, immunisation, health surveillance and screening. They can advise on issues such as bedwetting, soiling, emotional and behavioural aspects. They will inform parents and the family doctor if further action is required. Not all schools have a school nurse.

Support Assistant/Auxiliary –may work with your child if this is considered necessary. They may assist in the classroom, during breaks, at the start or end of the day or at gym.

Who's who in local authority children's and adult services

Your local authority has responsibilities towards children with additional support needs and their families and also adults with community care needs.



Care Assistant – can support you with the care of your child in your own home or if your child is having a short break outwith the family home.

Local Area Co-ordinators - have a special responsibility for working with families. They co-ordinate services and provide information, family support and funding to individuals and their families. They can

help individuals with learning disabilities develop a personal life plan. Not all areas have a local area coordinator at the moment.

Social Worker – can carry out an assessment of your and your child's needs for social support. They can help you to access a range of services from other agencies e.g. short breaks or housing.

Welfare Benefits Advisor – can support you to claim benefits to which you or your child may be entitled.

Sources of further information

Choosing a school: a guide for parents published by the Scottish Executive Education Department, Victoria Quay, Edinburgh EH6 600.

244 4485

*Download from http:// www.scotland.gov.uk

Top Marks for good practice: getting the most for your child's schooling, a checklist for parents - published by Scottish Consortium for Learning Disability, The Adelphi Centre, 12 Commercial Road, Glasgow G5 OPQ.

☎ 0141 418 5420 or email: administrator@ scld.co.uk

1 http://www.scld.org.uk

The parents' guide to additional support for learning - published by Enquire/Scottish Executive.

Enquire – The Scottish advice service for additional support for learning, Princes House, 5 Shandwick Place, Edinburgh EH2 4RG

Helpline:

≈ 0845 123 2303 or email: info@enquire.org.uk

1 http://www.enquire. org.uk

Parentzone – is a website for parents with information about schools, the curriculum, additional support for learning and more.

ttp://www. parentzonescotland. gov.uk ENABLE Scotland is the country's leading organisation for children and adults with learning disabilities, their families and carers.

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