

# Early Support

for children, young people and families

## Information about learning disabilities



## About this resource

This is an information resource for those who have recently been told that their child has a learning disability, are concerned about their child's development or are in the process of getting an assessment.

It was developed by [Early Support](#), in partnership with [Mencap](#), in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content, and the text reflects what parents who have 'been there' say they would like to have known in the early days of finding out about their child's situation.

This resource is designed to give you an introduction to the key things that you might want to know if your child has or might have a learning disability.

Some of the information in it will be relevant to you straight away. You may not think other parts are relevant yet; you can keep this resource and refer back to it when you need it.

The most important thing to remember is that your child is a child first and foremost. Your child is an individual and you will have different experiences to other parent carers and children you know.

If you have any queries about anything that is in this resource, or about learning disability in general you can contact [Mencap](#).

### Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young disabled people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in *Support and aspiration: a new approach to special educational needs and disability*, the government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of disabled children, young disabled people and their families.

Early Support helps local areas implement the government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about [Early Support](#), visit [www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport).

Where a word or phrase appears in colour, [like this](#), it means you can either: find the contact details for the organisation or agency listed in the [Useful organisations](#) section; or that you can find out more information in the [Who can help](#) section.

#### [Explanation of the term parent carer](#)

Throughout this resource the term 'parent carer' is used. This means any person with parental responsibility for a child or young person with special educational needs or a disability. It is intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

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## Has my child got a learning disability?

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

### What is a learning disability?

A learning disability is not an illness or a disease. It is a reduced intellectual ability, which makes everyday activities difficult (for children this can mean activities like getting dressed, communicating, personal care and sleeping). A learning disability affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

The level of support someone needs depends on individual factors, including the severity of their learning disability.

The term 'learning disability' describes significant delays in a child or young person's development. In a child's early years, it's unusual for practitioners to use the term 'learning disability'. You are more likely to hear terms like 'delay', 'developmental delay' or 'special needs'. You may hear the term 'learning difficulty', particularly as your child starts school. Special educational needs (SEN) categories use the term 'learning difficulty' not 'learning disability'. In this guide we will use the term learning disability.

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's syndrome), there is a genetic basis for their learning disability. However, for many children, even with a diagnosis, it is often not possible to say why they have a learning disability.

Children and young people with a learning disability tend to take longer to learn and may need support to develop new skills, understand instructions and to interact with other people. Some children and young people with a learning disability may take longer to develop language and social skills than their peers. Those who have a severe or profound learning disability and complex health needs may need support 24 hours a day for their whole lives (this is known as profound and multiple learning disabilities, or PMLD).

Everyone with a learning disability has a different level of need. As you get to know your child, you will learn what they struggle with and the support that can be put in place to help them. As they grow up, their support needs will change. As adults, some people with a learning disability need support with things like getting dressed, going shopping, or filling out forms; others do not need very much support in their lives.

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

It is important to remember that with the right support, most people with a learning disability can lead independent and rewarding lives.

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

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

### What to look out for

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

- Babies may have trouble nursing (for example sucking or digesting).
- In the early stages, children may show delays sitting and standing.
- Preschool children may be slow to talk, have difficulty pronouncing words and short sentences or learning new words.
- Children of school age may have difficulty reading and writing, and understanding information or instructions. They may have difficulty making friends and may need support with their social skills.

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

### Talk to your health visitor, GP or teacher

If your child seems to be taking longer to develop and you'd like some advice, talk to your [health visitor](#) or your [GP](#) first of all. They will talk through your concerns with you and may be able to reassure you. They may suggest that you monitor your child's progress together or they may refer you to a specialist.

If your child is at school and you have concerns about their development and progress, talk to your child's teacher or the school's special educational needs coordinator (SENCO). The SENCO is responsible for ensuring that a child with special educational needs (SEN) has those needs met as fully as possible. Both the SENCO and class teacher will be able to tell you about any additional support that they think your child may benefit from and how they can work with you to provide the support. They may also suggest that you monitor your child's progress together or they may refer you to a specialist.

### Keep up to date with your child's routine checks and appointments

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

over a period of weeks or months, or a referral to a specialist.

The Healthy Child Programme recommends that you are seen by your health visitor at a number of stages between your child's birth and their fifth birthday. These are only recommendations, but you should not be afraid to request appointments with your GP, health visitor or other practitioners at any stage. You could also raise any concerns you have when your child gets their vaccinations or if you visit a children's centre. Currently, the only check that your child must have is the Early Years Foundation Stage progress check at the age of two. This will be done by your child care provider, not a health practitioner.

As your child grows up and starts at nursery and school, there will be opportunities for you to talk to your child's teacher about their progress. You could use these times to raise any concerns you have. If you are worried about your child, you don't have to wait until a scheduled parents' evening. You can make an appointment with your child's teacher at any time. As your child gets older they will have regular reviews to keep track of their progress. You should be invited to these reviews and your child should be encouraged and supported to contribute, too.

## What does a learning disability mean for my child's potential?

Learning disability is a very broad term and in your child's early years it's very hard to predict how they will develop.

Someone with a mild learning disability may take a little bit longer to learn how to do things. They can access education in mainstream schools, although they may need some adjustments to help them.

Someone with a moderate learning disability may find it more difficult to speak. They may also need some support with looking after themselves. They should be able to access education in mainstream schools too, but might require more adjustments to be made.

Someone with a severe learning disability may never learn to speak, but will be able to communicate in their own way. They may be able to attend a mainstream school, with the right support, although you may choose to send them to a specialist school.

### Every child's learning disability is different

Your child's learning disability will be individual to them. Most children with a learning disability experience delay in more than one area. For example, their communication may develop slowly as well as their progress in learning to dress and undress.

Development can be 'bumpy' for some children, meaning they make good progress for several months and then level off for several months.

Some children with a learning disability may also have sight or hearing problems, which will also affect their overall development.

### Every child is an individual

*"Remember your child is 'your child'. Do not label him/her. He/she is not a type; not a syndrome; just one of your children. Do not see him/her as different from your other children. Expect him/her to achieve anything, but understand when this is not possible."*

Parent

Other people might see the disability first, but as long as you see your child as a child first, it will help others to see past the disability and give your child confidence to face any challenges that come their way.

## In the beginning

Everyone reacts differently when they are told that their child has, or might have, a learning disability. Some parent carers will feel relieved that support can begin to be put in place, others will be upset by the news and may even look for someone to blame. Everyone will react differently; there is no right or wrong way. There are lots of places where you can find support to help you come to terms with your own feelings and understand your child's learning disability, and what this means for your family and your child.

Support can come in a variety of forms. It might be from your friends and family, services you come into contact with, voluntary organisations, support groups and other parent carers. If you do not know any parent carers of children with a learning disability, there are online communities that you turn to for advice.

However, it is important to bear in mind that every child and young person is different, and everyone's experiences of services will differ. Some services will work for you and your child, and others may not. If something doesn't seem to be working for your child, don't be discouraged; by finding out what doesn't work, you're one step closer to finding out what does work.

There is a list of organisations you may find useful at the end of this resource.

## Other people in your child's life

### Family and friends

Some people may not understand when you tell them that your child may have a learning disability. They may need your help to understand what it means and the extra support that your child needs. It may be helpful to share this guide with them. Friends and family can be an invaluable support to you, your child and their siblings. For your well-being, and your child's, it is important to maintain positive relationships and to take care of yourself. Those close to you may be able to offer support and care for both you and your child.

As your child grows and their support needs develop and change, it is important that you pass on any information about your child to your friends and family so that they are able to offer your child and you the support that you need.

### Siblings

If your child has brothers or sisters, they will be one of their biggest supporters, but as with all siblings, they will fall out, squabble and argue.

It is important that you explain to them about their sibling's learning disability. They may worry that they will get a learning disability, but it is important to tell them that a learning disability is something people are born with and that growing up with someone who has a

learning disability can be great fun. Reassure them that it's OK not to want to play with their brother or sister all the time and it's OK to get annoyed. They may find it difficult bringing friends home or feel angry that you are spending more time with their sibling than with them. It is important that you recognise their feelings and help them find a way to deal with them. The charity [Sibs](#) can offer help with this.

### **Other people your children meet**

Your child will meet lots of people as they grow up and most of them will not be experts in learning disability. If your child does activities in their free time, don't be afraid to talk to the organisers about what they can do to support your child. Pass on any relevant information about your child and their needs, and keep everyone up to date with any changes that happen. There are some helpful tips about supporting services to meet your child's needs later in this resource.

Some people might not need to know very much about your child's needs, but others will benefit from knowing more in-depth information about your child's disability. As your child grows up and becomes more independent, they may attend activities where they spend lots of time away from you. In this situation, everyone will benefit from understanding a lot about your child.

## What can I do to support my child?

If your child has a learning disability, there are plenty of things you can do to support them. Much of what you can do is the same as you would do for a child without a learning disability. The main difference is the length of time it takes for your child to move from one stage of development to another.

As your child develops and you get to know each other, you will be able to judge how you can help them more specifically. But here are a few things you can do to help both you and your child:

- **Don't be afraid to ask questions** – You will meet a lot of practitioners as your child grows. Some will be helpful and others may not be. Remember, they are there to help you and your child, and will be happy to answer any questions or queries you have.
- **Learn about your child** – You are the expert on your child. You know what your child likes doing and will be able to use this knowledge to help them learn new things. If you have a diagnosis, it may be helpful to find out about your child's condition. But remember, your child is a child before any condition or label.
- **Include and encourage your child** – Include them in family life, in your conversations and activities. Encourage them to communicate and participate. Read to them and with them. Offer them choices; even choosing simple things like which book to read at bedtime will help them to develop confidence and other skills. They will be learning and developing all the time.
- **Think about how you communicate** – If your child has difficulty with speech, there are other ways you can support communication. There are some useful tips later on in this guide.
- **Don't give up** – If an approach you are taking doesn't seem to be working, it may be that there are other ways you can support your child and help them to develop. If you are not getting the support you think you need, keep asking.

## How can I support communication?

Developing good communication skills is really important for all parent carers and their children. Communication is the way that your child will tell you that they are hungry, happy, tired or scared, and everything else in between. Good communication will also help manage your child's behaviour.

If you use a language other than English at home and your child responds to this, it's useful to share this with practitioners. Other people working with your child will benefit from knowing what works for you in your home and the community, and can use this to strengthen their communication with your child.

It is important that you communicate with your child in a way that is appropriate to them. Your child will find it frustrating if they cannot be understood and this can lead to challenging behaviour, which is another form of communication. Be patient with your child and take the time to understand what they are trying to tell you. As you and your child get to know each other you will get better at this!

### **When they are young**

Babies start to communicate before they can speak, and your child will be no exception. They will communicate using smiles, by making sounds and by pointing. They may communicate in other ways and you will soon learn what your baby is telling you. This will happen as you learn more about each other. Spending time with each other and watching your baby will help you.

Just as you will learn about how your child communicates, they will learn about communication from you. They will learn that it is a two-way process and that when they communicate, you respond. This response may be verbal, it may be that you feed them or change their nappy, or it might be that you respond with physical touch. This will show your baby approval and support, as well as important lessons about communication.

### **As they get older**

Instructions and requests should be clear and concise. Don't try to link two instructions together – ask them to wash their face first and then ask them to brush their teeth.

Use simple language and, wherever possible, use body language, signs or symbols to reinforce these requests.

Many children, young people and adults with a learning disability have an auditory processing delay. This means it can take them some time to understand the meaning of the most basic sentence. This is why it is important to wait before repeating instructions, and to ensure you speak as clearly and concisely as possible.

Give your child plenty of warning of anything that is expected of them and give them time to do what they've been asked. They may not be disobeying you, they are likely to be processing the information you have given them.

### **Additional support and communication techniques**

If your child uses additional communication techniques, it may be helpful to make materials available to your friends and family so that they are also able to communicate with your child.

## **Alternative and augmentative communication (AAC)**

AAC is an umbrella term that describes the different methods that can both replace and supplement the spoken word. People with more severe learning disabilities may not be able to speak, but can use a number of methods to communicate. These might involve using electronic equipment that can speak for the user – the user inputs what they would like to say using a keyboard.

### **Makaton**

**Makaton** is a way of communicating using signs and symbols. It is designed to support, not replace, spoken language. You use the signs and symbols with speech, in the order that the words are spoken. Symbols and signs can be dropped as your child develops speech.

### **Picture Communication Symbols (PCS)**

PCS are a set of colour and black and white drawings. These are used in AAC systems. They can be used electronically or with a communication board, which can be a board with symbols on that the child or young person will point to, to indicate what they want to say.

They are often used by children and young people who have little or no speech. There are roughly 5,000 symbols in the PCS set. Symbols represent a word or idea in a picture format. Children will either point to or hand the symbol to you to express something.

People can develop their own symbols if the needed symbol is not available. This means PCS can be adapted to ensure that the symbols are culturally and personally relevant to your child.

For more information about speech, language and communication, please see the Early Support resource *Speech, language and communication needs* at [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

## **How can I support play and having fun?**

Even though your child may have a learning disability, they will still like the same things as other children – making friends, taking part in cultural activities, getting out and about, and playing and learning. They will benefit from playing with other children and having new experiences.

Don't be afraid to take your child to the local swimming pool, the leisure centre, playgroup and to other activities. Your child will be welcome at all these places, but they may not know how to adapt to the needs your child automatically. Here are some ways that you can support services to include your child:

- Get in touch to let them know that you are coming and of any needs that you might have. It will give the staff a chance to make any adjustments before you arrive.

- Offer to bring equipment from home to help support your child. For example, if you know that your child's wheelchair won't fit under the tables at the service, you could bring a lap tray so they can sit with the other children and join in.
- Accommodating your child may be second nature to you, but it might not be to staff at other services. Don't get angry if they make a mistake – just explain calmly and patiently why something may be a problem and work out how to fix it together.
- If you are taking your child to a place that they can be left, you might decide to offer to stay for the first time they are there. Chances are the staff will happily send you away, but they may appreciate a bit of support while they are getting to know your child.

### **When they are young**

Play is fun – children love fun and stimulation and your child will just enjoy playing and spending time with you.

Play is an important part of young children's development. It gives them a chance to learn, develop and explore their surroundings. Very young babies play too – there are simple games that you can play, like peek-a-boo. This will help with attachment as well as other developmental needs.

Early play, with simple toys, can help to develop emotions and mobility. As they get older, playing with other children will help them learn about other people's feelings and other social skills, such as sharing.

Play can be a useful tool to encourage children to develop skills. It teaches children about problem-solving, decision-making and the world around them. Every child is different and develops differently. They will also have different interests and ways to play, and different things they struggle with.

### **When they are older**

As your child gets older their idea of play will change. Some children will be very sociable and want to spend lots of time with other children and young people. Others might not be quite so sociable and prefer more solitary activities.

Play and other activities teach children and young people about risk in a controlled environment. This is an important thing for all children and young people to learn. Trying new things lets children find out what they're good at and what they enjoy. This will help them as they get older and start thinking about what to do when they leave education.

Give your child opportunities to try new things and if they express an interest in trying something new then try to support this as much as possible. Your local Family Information Service can help you find activities that are suitable for your child and may be able to support the setting if it needs a little bit of help meeting your child's need. You might also

be able to get funding, or support through short breaks. For more information about short breaks see the [Who can help](#) section.

As your child gets older, they may develop a special interest. They should be encouraged to develop this interest, although you should continue to encourage them to do other activities that they enjoy, too. Special interests are often a good way to reinforce your child's learning and to develop their skills. If your child does develop a special interest, it may be useful to share this with your child's teacher.

## What other families found helpful

### Give yourself time

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

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

Also, take time for yourself (and your partner if you have one). One of the most important things you can do for your child is to take time out so that you can relax. Just taking a little bit of time to yourself regularly can help to ensure that you are able to support your child.

### Don't go through it alone

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

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

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

You may also find that parent and toddler, baby massage and other groups provide valuable support networks, and offer your child new and exciting experiences as well as a chance to make friends.

### Look for local support

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

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

## Do what you think is best for your child

*“One of my big regrets is that my child was hived off into specialist service land from when he was a few days old. It continued for many years and there were many tears and frustrations. I wish that someone had been standing alongside and said, ‘Your child is a child like any other and can join in growing up with his peers in school and society.’”*

Parent

It can be difficult to disagree with practitioners and experts, especially as you trust them to do what is right by your child. But don't be afraid to ask questions about what is happening. If you are not happy about something, ask to discuss it. It might not change what is happening, but it may make you more comfortable. They may be able to find other solutions. Don't be afraid to remind them that their patient is a child or young person before anything else.

## Find out about the different ways you can access support

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

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

There are various ways to get financial help if you need it, such as tax credits. Find out more about some of the financial help available in the Early Support background information resource on financial help – visit [www.ncb.org.uk/early-support/resources](http://www.ncb.org.uk/early-support/resources).

## Have a plan

*“My advice for other parents would be: don't panic. Start making plans for every stage of your child's life and keep these plans up to date.”* Parent

Your child may have a number of plans with different health, education and other practitioners. Make sure these plans are up to date, are made with you and your child's input and actually happen. As your child grows up, plans will change, and so will the practitioners you work with. Plan ahead for each stage, so that when you get there you know what is meant to happen and who you need to speak to.

If you are working with a lot of practitioners, you might be able to access a key worker to help you access appointments. You can find out more about this from the Early Support website [www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport).

There are tools that you can use to assist you when working with lots of practitioners. This is also called multi-agency working. The Family File is a tool that consists of a number of standard, flexible templates, which can be filled in and used by families, or by families and practitioners working together. It includes a Family Service Plan, which encourages all the agencies working with a family to discuss the support that is being provided and to agree priorities.

## Work with specialists to help you and your child

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

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

*“The assistance in the Early Years Centre ensured that our child’s whole needs were met. Staff supported his Pakistani, British and Muslim identity, and he saw his home language supported in the setting, too. It made a real difference to his development and our life as a family.”* Parent

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

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

## Education

### Early years education and play

Like any child, children with a learning disability benefit from learning through play from a very early age. This type of learning starts at home and carries on into early years education provision.

- **Portage services**

Portage is a home-visiting, educational service for preschool children who need extra support, and their families. These services are generally provided by your local education authority, but are not available in every local area. They can support you to play with your child at home, and use play to teach new skills.

- **Children's centres**

Children's centres are a valuable resource for parent carers. They offer sessions like baby massage and play sessions, and many have sensory rooms and sessions aimed at parent carers of children with disabilities. Midwives and health visitors often hold clinics at children's centres, and there may be speech and language therapists attached to them as well. The centres may also be able to offer information and support regarding benefits, looking for work and childcare options.

- **Nursery and childcare provision**

Your child will be entitled to part-time early years education. You can find out from what age your child qualifies and the amount of time that they are entitled to from your local [Family Information Service](#).

### Primary education

#### Choosing a school

Choosing a school for your child is a big decision for any parent carer. The first step is to find out exactly what schools are available in your area – you can get this information from your local authority. Your local authority can also put you in touch with the local [Parent Partnership Service](#), which can give you information and advice about getting your child's educational needs met.

You may already know where you want your child to go to school. You might find it useful to consider the following questions:

- How will the school support your child's needs? You can ask the school questions

about this.

- Are any of your child's friends going to the school, too?
- How far is the journey? Will your child be able to walk, or will they need transport?
- Where does your child want to go? They won't be making the final decision, but they will be able to tell you if they like or don't like a school.

You will probably find that your child can get the support they need from their local school. However, if your child has complex needs you may want to consider a school that caters for children who need more specific support. Schools are required to make reasonable adjustments to meet your child's needs, so you shouldn't have to rule a school out just because they don't appear to be able to cater for your child. It may be helpful to take advice from your child's practitioners about the kind of school that is best for them. Your child may also have an opinion. For example, they may like to go to school with their friends, and they may want to come with you on a visit.

## Assessments

Your local authority's education department may assess your child to make sure they get the right support and are able to learn. Your child will have to be referred for an assessment, but there are different people who can do this. You will be able to do this yourself, but you should speak to your child's school or early education provider in the first instance.

If your child is assessed as having special educational needs (SEN) and needing additional support, they will be given a plan that lays out the additional support they need and identifies outcomes that your child will be working towards. Again, if you have any queries, it is best to ask your child's school or early education provider as they will be able to advise you on the support they already offer and your options. Your local [Parent Partnership Service](#) should also be able to advise you.

If your child is given a plan, this should be reviewed annually. Both you and your child should be invited to contribute to the review. Your child should be supported appropriately to do this.

If you are unhappy with the support your child is getting, or your child is unhappy at school, you should speak to the school. If you have other worries concerning the assessment process, there are organisations that can give you specialist and legal advice. Their details are at the back of this resource.

## Secondary education and beyond

### Moving from primary to secondary education

When you are choosing a secondary school, you will have lots of people to ask for advice and a lot more experience of your child's needs, strengths and weaknesses. You will be

able to ask the practitioners who have been involved with your child, friends and, of course, your child.

Changing schools is likely to be a big deal for your child. It is important to give them plenty of time to get used to the idea of moving schools and all that comes with it.

If your child is travelling independently to school, practising their route and using public transport will help them feel confident. It will also help to reassure you that they know what to expect and what to do if they get lost.

If your child is travelling by school bus or taxi, show them the route and the things they will pass on the way. Can you show them the type of bus they will be travelling in? You could see if it's possible for them to meet their bus or taxi driver before their first day.

Your child may also have to get used to a new uniform. Practising putting it on and taking it off will help them get used to how it feels and how to get ready.

Your child's primary school teacher will meet with the SENCO from the secondary school to hand over their records and important information about your child. The secondary school will want to help your child settle in, so might arrange special visit days for its new pupils.

If your child is going to a school away from their friends, they may feel worried that they are not going to see them anymore. Try to arrange a time for them to see their friends again and reassure them that they will make friends at their new school.

## **Moving into adulthood**

Moving into adulthood can be a daunting time for parent carers and young people alike. Leading up to this, young people should have transition reviews to prepare them for the future. This will help them make decisions about what they want to do next, where they want to live and their plans for the future.

Young people should be supported to make meaningful decisions and express their own desires and choices. Some young people with a learning disability may find it difficult to make decisions about things that they have little or no experience of. Trying new things and lots of visits can help.

## **Benefits, finding work and extra help**

### **Benefits**

There are a range of benefits and tax credits that you may be able to claim as the parent carer of a child with a learning disability, and that your child will be able to claim for themselves as they grow up. For more information about the benefits you can claim, visit [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits). For help with filling out forms, you can contact [Contact a Family](#) or [Mencap](#).

## Finding work

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

Mencap supports young people and adults with a learning disability to develop their employability skills and find work. Support is also available from the government for people with disabilities and additional needs. You can find out more information at [www.gov.uk/access-to-work/overview](http://www.gov.uk/access-to-work/overview) or at the Jobcentre Plus office.

## Extra help

Your local authority may be able to offer you extra help in other ways. You might have to pay for it, but it could be help in your home or the opportunity for your child to spend a few hours being looked after away from home. Don't forget to check your local authority's local offers to see what they provide, and seek advice to see what you're entitled to.

If you want your local authority to arrange and pay for extra help, contact your local authority's social services department to see if you are eligible for help.

## Growing up and being included

As your child gets older, they may be faced with barriers to inclusion. These may change as your child grows up. Spending time with your child in the community and building a network of friends around them can help to overcome these barriers, and is beneficial to everyone. If children are used to playing with your child from an early age, they will accept, and expect your child to be allowed to play with them as they get older.

It is also important to manage your child's expectations. While they should be able to participate in most activities with their friends, if your child uses a certain type of wheelchair, or doesn't enjoy contact sports, playing rugby on a muddy field may not be an option. If they can't sing in tune or hate noisy environments, maybe the choir just isn't for them.

Your child has a right to access activities in your community, and for adjustments to be made to include them. But just like any other child, there will be times when they won't win the race or get picked for debate team. Supporting your child to understand and learn from these experiences will be of great benefit to them as they are growing up. It will allow them to identify the difference between discrimination and everyday bad luck, as well as encouraging them to identify and develop areas where they have talent.

Your child may also face challenging attitudes and behaviour. Discrimination against disabled people is not acceptable and your child should be supported to understand this. They should not feel that they have to accept such ill-treatment, or that they have to deal with it themselves. The support networks that you are beginning to put in place now while your child is small will be important in helping them to face and overcome these challenges.

It is also important to remember that the challenges a child with a learning disability may face will almost certainly be faced by their siblings. A sibling may feel they have to stand up for and defend their brother or sister, and may risk being bullied themselves. Just as your child with a learning disability will be helped by a robust support network, a strong network for their siblings is important, too.

There is also plenty of help available from support groups and other organisations like [Mencap](#) and [Sibs](#).

## 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 practitioners and organisations that can give you advice, counselling and very practical help.

### Health practitioners

Like all children, your child will have a lot of contact with health practitioners. Some contact may be specific to your child's needs, while other contact may be just because they are a child. Here are some of the health practitioners you may meet:

**Continence Advisor** – A qualified nurse who specialises in bladder and bowel problems. They should be able to advise you about getting free nappies and pull-ups.

**GP** – A family doctor who works in the community. They are the first point of contact for many families and provide a general child health service, including immunisations. Your GP will be able to point you in the right direction if you need extra support and can also refer you to a range of specialists, such as paediatricians, learning disability nurses, child development teams or therapists.

**Health visitor** – A health practitioner who visits the family home in the early years of a child's life to check on their health and development. You should automatically receive a visit from a health visitor when your child is born. If you don't, your GP can arrange one for you.

Health visitors can give you help and advice about the care of very young children, child development, feeding and sleep, behaviour and safety. They can also help you find out about childcare and specialist help for your child. Your health visitor is there for the whole family and can help you think about what you all need.

**Learning disability nurse** – A specialist nurse who works with children, young people and adults with a learning disability, and their families. Your GP can refer you if you need one. They support the well-being and social inclusion of people with a learning disability.

**Paediatrician** – A doctor who specialises in children's health. Your GP can refer you if you need one. Paediatricians may see your child to assess their learning disability or to monitor their health and progress. They can offer advice, information and support about any medical condition(s) your child has.

They may also refer your child to other specialists, for example, a clinical psychologist or a child development centre, where their health, social and educational needs will be considered in detail. Some areas also have community-based paediatric nurses who can

visit you at home and work closely with the whole family.

**Clinical psychologist** – A health practitioner who can help children and young people with specific challenges when learning new skills and to overcome behaviour that is challenging. Your GP or paediatrician can refer you if necessary.

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

**Therapist** – A health practitioner who works with all kinds of people, including children and young people with a learning disability. There are a number of different types of therapist and your GP will refer you to the most suitable one:

- **Speech and language therapist** – Helps with communication problems and associated eating and swallowing difficulties. They can offer support and advice to parent carers of children and young people with any type of communication problem, and help them to develop their communication, language and speech.
- **Physiotherapist** – Helps children or young people with their movement. Physiotherapists will look at any challenges your child has with movement and set a programme of physiotherapy that will help them. For example, they might improve a child's head control or their ability to sit with support – helping them to prop themselves up on their hands.
- **Occupational therapist** – Assesses a child's skills at play, school and day-to-day tasks to help them improve. For example, they can help children with a learning disability to develop hand-to-eye coordination and improve grip using building blocks, so they can grasp toys and get more out of play.

As well as your GP, you can ask social services for an appointment.

## The local authority

Local authorities can help you and your family get the support you need. Some local authorities have a children's disability register. Parents do not have to register their children, but local authorities use them to understand the needs of the local community. Registration is based on the level of care and support that a child needs, not their diagnosis. Here are some of the services offered by local authorities:

**Family Information Service** – Your local authority's Family Information Service can put you in touch with other helpful agencies and parent carer support groups. They will also have information about childcare, opportunity groups, nurseries and children's centres.

**Local offers** – Local authorities are supposed to provide details of all the services that they offer. These are called 'local offers' and should be available on your local authority's website.

**Portage** – This is a home-visiting, educational service for preschool children who need extra support, and their families. These services are generally provided by your local education authority, but are not available in every local area. They can support you to play with your child at home, and use play to teach new skills. They are also mentioned later in this resource. To see if you have a portage service near you, check your local authority's local offers, or the [National Portage Association's](#) website.

**Short breaks** – These services provide short breaks to disabled children. They support disabled children to engage in new opportunities, meet new people, increase their independence skills and get involved in new things in their community. Short breaks also give disabled children's families a break from their caring responsibilities. They come in all shapes and sizes. They can be anything from enabling you to take a short break together as a family away from the routine of daily life, to providing a break for your child away from you. They can also boost confidence, introduce new family experiences and be important for the family's well-being.

Local authorities have a duty to provide details of their offers of short breaks. This information should tell you what the service offers are and how you can access them, including any eligibility criteria that they have. As your child gets older and their needs change, the type of short break that you access may also change, particularly as they will have their own ideas about what they want to do.

**Social workers** – They provide practical help and advice, and may be able to help you with claiming welfare benefits and equipment.

## **Education practitioners**

**Educational psychologist** – Offers consultation, advice and training on how schools, early years settings and parent carers might help children to learn effectively and make the most of their education. They can suggest different teaching and learning approaches that may help your child learn more effectively.

**Special educational needs coordinator (SENCO)** – Takes day-to-day responsibility for the provision made for each child with SEN. They will work closely with staff, parent carers and other agencies. They provide advice and support to individual teachers about how to meet children's needs in the classroom.

## **Other practitioners and organisations**

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 end of this resource.

## Top tips

- **Remember your child is a child first** – Other people might see the disability first, but as long as you see your child as a child first, it will help others to see past the disability, and give your child confidence to face any challenges that come their way.
- **Your child should understand that no one has the right to treat them differently because of their disability** – In the same way that no one has a right to treat anyone differently because of their sex, sexuality or race.
- **If you are concerned, seek advice** – If your child seems to be developing more slowly, you have concerns, or you'd just like some advice, talk to your [health visitor](#) or your [GP](#) first of all. They will talk through your concerns with you and may be able to reassure you.
- **Everyone is different** – Every child and young person is different, and everyone's experiences of services will differ. Do not be put off by one negative story.
- **Become an expert on your child** – You will know what your child likes doing and will be able to use this knowledge to help them learn and develop. Don't be afraid to use this expertise to help practitioners support your child.
- **If in doubt, ask** – Don't be afraid to ask questions if you don't understand something, or to ask if you need more help or support. If you think you should be getting something that you are not, there are organisations that you can ask about your rights. For contact details, turn to the [Useful Organisations](#) section of this resource.
- **Develop your communication skills** – If your child has difficulty with speech, there are plenty of other ways to support communication. It may be that you just haven't thought about them yet!
- **Manage expectations** – Don't be afraid to have high expectations, but ensure they are realistic. People with learning disabilities have gone on to do some amazing things. Help your child to have their own aspirations and goals.
- **Don't give up** – The first time you try something with your child it may not work. It may be that you need to take a different approach.
- **Don't forget the siblings** – They will face their own challenges and will need to be supported and have things explained to them in a way that they can understand.

## Useful organisations

We have tried to put together a resource that offers you some initial support and advice that may be useful to you. Parts of it may not be relevant to you just yet. It is designed to be picked up, put down, shared and discussed. You will probably still have many questions, but there are lots of places that you can go for help.

Over the next few pages we have compiled a list of organisations that may be able to support you, your child and your family. The list is not exhaustive, but should provide you with a starting point for advice, information and support.

### Advisory Centre for Education (ACE)

An independent advice centre offering information about state education in England and Wales. Although most of its information relates to children over five, it can advise on special education for younger children.

ACE Education Advice & ACE Education Training

36 Nicholay Road

London

N19 3EZ

[www.ace-ed.org.uk](http://www.ace-ed.org.uk)

[enquiries@ace-ed.org.uk](mailto:enquiries@ace-ed.org.uk)

020 84075142

### Afasic

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

Afasic

1st Floor

20 Bowling Green Lane

London

EC1R 0BD

[www.afasic.org.uk](http://www.afasic.org.uk)

[info@afasic.org.uk](mailto:info@afasic.org.uk)

Helpline: 0845 355 5577

020 7490 9410

### **Carers UK**

This is run by carers to provide support to anyone who is a carer. It offers information and advice, produces a range of publications and also campaign for carers' rights.

Carers UK  
20 Great Dover Street  
London  
SE1 4LX

[www.carersuk.org](http://www.carersuk.org)

Carers Advice line: 0808 808 7777  
020 7378 4999

### **Children Today**

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

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

[www.children-today.org.uk](http://www.children-today.org.uk)

[info@childrentoday.org.uk](mailto:info@childrentoday.org.uk)

01244 335622

### **The Communication Trust**

A coalition of nearly 50 voluntary and community organisations with expertise in speech, language and communication. It supports the children's workforce and commissioners to meet the speech, language and communication needs of all children and young people.

The Communication Trust  
8 Wakley Street  
London  
EC1V 7QE

[www.thecommunicationtrust.org.uk](http://www.thecommunicationtrust.org.uk)

[enquiries@thecommunicationtrust.org.uk](mailto:enquiries@thecommunicationtrust.org.uk)

020 7843 2526

### Contact a Family

A UK-wide charity providing support, advice and information for families with disabled children. It runs a helpline for family members and can also help you get in touch with other parent carers of disabled children living near you.

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

[www.cafamily.org.uk](http://www.cafamily.org.uk)

[helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

National freephone helpline: 0808 808 3555

Textphone helpline: 0808 808 3556

020 7608 8700

### Coram Children's Legal Centre

Provides free legal information, advice and representation to children, parent carers and their families.

Coram Children's Legal Centre  
38 Great Portland Street  
London  
W1W 8QY

[www.childrenslegalcentre.com](http://www.childrenslegalcentre.com)

Family, child and education legal advice line: 08088 020008

### Down's Syndrome Association

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

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

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

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

0333 1212300

### Early Years Equality

Provides disability equality and other protected characteristic equality support, guidance, advice, discrimination casework and training to children, families, organisations, providers and policymakers across the UK.

Early Years Equality

Aizlewoods Mill

Nursery Street

Sheffield

S3 8GG

[www.earlyyearesequality.org.uk](http://www.earlyyearesequality.org.uk)

[enquiries@earlyyearesequality.org.uk](mailto:enquiries@earlyyearesequality.org.uk)

0114 270 0214

### Equality and Human Rights Commission

It has a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine 'protected' grounds – age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment.

FREEPOST Equality Advisory Support Service FPN4431

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

[englandhelpline@equalityhumanrights.com](mailto:englandhelpline@equalityhumanrights.com)

0800 444205

Textphone: 0800 444206

### Family Fund

Helps families across the UK who are raising a disabled child or young person with additional complex needs or a serious illness.

Family Fund

4 Alpha Court

Monks Cross Drive

York

YO32 9WN

[www.familyfund.org.uk](http://www.familyfund.org.uk)

[info@familyfund.org.uk](mailto:info@familyfund.org.uk)

08449 744099

### **Include Me TOO**

Supports disabled children, young people and their families from Black, Ethnic Minority and other marginalised community backgrounds, and supports and promotes social justice, equality and rights for all disabled children and young people.

Include Me TOO

Newhampton Arts Centre

Dunkley Street

Wolverhampton

WV1 4AN

[www.includemetoo.org.uk](http://www.includemetoo.org.uk)

01902 399 9888

### **Independent Parental Special Education Advice (IPSEA)**

An independent organisation, working across England and Wales, providing free advice to parent carers about local education authorities' duties to assess and provide for children with special educational needs.

[www.ipsea.org.uk](http://www.ipsea.org.uk)

Helpline: 0800 018 4016

Tribunal helpline: 0845 602 9579

### **Kidscape**

A charity that is committed to keeping children safe from abuse. It is the first charity in the UK established specifically to prevent bullying and child sexual abuse.

Kidscape

2 Grosvenor Gardens

London

SW1W 0DH

[www.kidscape.org.uk](http://www.kidscape.org.uk)

[webinfo@kidscape.org.uk](mailto:webinfo@kidscape.org.uk)

Helpline: 08451 205204

020 7730 3300

### **The Makaton Charity**

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

The Makaton Charity

Manor House  
46 London Road  
Blackwater  
Camberley  
Surrey  
GU17 0AA

[www.makaton.org](http://www.makaton.org)

[info@makaton.org](mailto:info@makaton.org)

01276 606760

### **Mencap**

Mencap is the UK's leading learning disability charity. Everything it does is about valuing and supporting people with a learning disability, their parent carers and families. It works with people with a learning disability across England, Wales and Northern Ireland to change laws and challenge prejudice. The services it provides, in things like housing, employment, education and personal support, gives thousands of people the chance to live their lives as they choose. Call its helpline or visit its website for factsheets, guides, useful contacts, information about funding, services and the Mencap carer's network, and to read blogs from other families.

Mencap

123 Golden Lane  
London  
EC1Y 0RT

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

[information@mencap.org.uk](mailto:information@mencap.org.uk)

Learning disability helpline: 0808 8081111

Learning disability minicom helpline: 0808 8088181

### **The National Autistic Society**

A UK-wide charity for people with autism (including Asperger's syndrome) and their families. It provides information, support and services.

The National Autistic Society

393 City Road  
London  
EC1V 1NG

[www.autism.org.uk](http://www.autism.org.uk)

[nas@nas.org.uk](mailto:nas@nas.org.uk)

020 7833 2299

### **The National Deaf Children's Society**

An organisation of families and parent carers providing emotional and practical support through a variety of ways. It offers impartial information and individual advocacy on every aspect of childhood deafness.

National Deaf Children's Society

15 Dufferin Street

London

EC1Y 8UR

[www.ndcs.org.uk](http://www.ndcs.org.uk)

[ndcs@ndcs.org.uk](mailto:ndcs@ndcs.org.uk)

020 7490 8656

Minicom: 020 7490 8656

### **National Family Information Service**

A registered charity that supports, links and promotes Family Information Services (FIS) in Great Britain. Your local FIS provides a range of information on all services available to parents, to help you support your children up to their 20th birthday, or 25th birthday if your child has a disability. It also holds up-to-date details of local childcare and early years provision in your area.

Daycare Trust

2nd Floor, The Bridge

81 Southwark Bridge Road

London

SE1 0NQ

[www.daycaretrust.org.uk/nafis](http://www.daycaretrust.org.uk/nafis)

[info@daycaretrust.org.uk](mailto:info@daycaretrust.org.uk)

0845 872 6260

### **National Network of Parent Carer Forums (NNPCF)**

The NNPCF works to ensure that good practice, knowledge and shared expertise about parent participation grows and develops, through Parent Carer Forums across England. Together with Local Parent Carer Forums, it identifies common priorities and ensures that information and experiences are shared so that service delivery can be influenced at a national level.

[www.nnpcf.org.uk](http://www.nnpcf.org.uk)

### **National Parent Partnership Network**

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

National Parent Partnership Network

8 Wakley Street

London

EC1V 7QE

[www.parentpartnership.org.uk](http://www.parentpartnership.org.uk)

[nppn@ncb.org.uk](mailto:nppn@ncb.org.uk)

020 7843 6058

### **National Portage Association**

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

National Portage Association

Kings Court

17 School Road

Birmingham

B28 8JG

[www.portage.org.uk](http://www.portage.org.uk)

[info@portage.org.uk](mailto:info@portage.org.uk)

0121 244 1807

### **NATSPEC**

An association for independent specialist colleges that provide further education for students with learning difficulties and/or disabilities.

[www.natspec.org.uk](http://www.natspec.org.uk)

0117 923 2830

### **Sibs**

This charity represents the needs of siblings of disabled people. It supports siblings of all ages who are growing up with, or who have grown up with, a brother or sister with any disability, chronic illness, or life-limiting condition. It offers information and support to parents and siblings.

Meadowfield

Oxenhope

West Yorkshire

BD22 9JD

[www.sibs.org.uk](http://www.sibs.org.uk)  
[info@sibs.org.uk](mailto:info@sibs.org.uk)  
01535 645453

# Early Support

for children, young people and families

[www.ncb.org.uk/earllysupport](http://www.ncb.org.uk/earllysupport)

Funded by



Department  
for Education

We acknowledge with thanks  
the contribution of the  
following organisations in the  
production of this resource



**Early Years Equality**  
*removing racism • defying discrimination*

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2<sup>nd</sup> edition