

## Information about deafness and hearing loss



## About this resource

This information resource is for parent carers with children up to the age of 25 who are deaf. It contains information about your child's deafness and how it will affect you and your child. The term 'deaf' is used to mean any level of permanent or temporary hearing loss, from mild to profound, in one or both ears.

This resource was developed by the [National Deaf Children's Society \(NDCS\)](#) for [Early Support](#). Families were consulted about the content and the resource reflects what parent carers of deaf children said they wished they had known. Deaf young people also told us what information they thought was most important for their families to know.

This resource contains chapters on what happens in the beginning, when your child is identified as being deaf, and then explains what deafness means. The resource goes on to outline things to think about as your child moves from the early years to school years and into adulthood. The resource finishes with chapters on who can help, resources, and useful organisations and websites.

Parent carers of deaf children can dip into the chapter most relevant to them or read the whole resource cover to cover. Some issues remain the same regardless of the age of your child, therefore there is repetition in some of the chapters.

This resource can be used on its own or with the [Early Support](#) publication, *Monitoring protocol for deaf babies and children*. You may want to read more detailed resources on specific topics from [NDCS](#) or other voluntary organisations – some useful resources are suggested.

### 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 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 and young 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/earlysupport](http://www.ncb.org.uk/earlysupport).

Where a word or phrase appears in colour, [like this](#), it means you can: look them up in the [Glossary](#) at the back of the resource; find contact details for the organisation or agency highlighted in the [Useful organisations and websites](#) section; or find out more in the [Who can help](#) section.

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

Throughout this resource the term 'parent carer' is used. It 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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## In the beginning

### Identification

When some families are told their child is deaf, it can be a great shock. Some parent carers will be upset by the news; others will be relieved that their suspicions have finally been confirmed. Some parent carers may come from a culture or community where **additional needs** are viewed in a negative way. You will have your own reactions. There is no right or wrong way to feel.

At first, you may spend time identifying what steps you will need to take to support yourself and your deaf child. It can be difficult to remember all the information that **practitioners** give you. Do not be afraid to go back and ask questions when you have had time to think. If English is not your first language and you are not fluent in English, you should request an interpreter when working with practitioners to ensure that you fully understand them.

*“The **audiologist** talked to us for a while. I have to admit that I didn’t hear a single thing after the word ‘deaf’. They were really good though and I went back to see them the next day and they explained everything again.”* Parent

It is important to know that you are not alone. A wide range of support is available from different people and places, including family and friends, your local community, services for deaf children, voluntary organisations and charities, such as **NDCS**, and other parent carers of deaf children.

The **NDCS** freephone helpline can help you identify support in your area. Call 0808 8008880 (voice and text), or e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

### Feelings and looking after yourself

It is important that you take time to look after yourself and even more important that you acknowledge how you are feeling. Your own health is vital. The birth of a new baby involves a combination of emotions and so does discovering that your child is deaf. If you feel a sense of loss, then grief is a healthy reaction to this; the strength of your reaction depends on how big the loss seems to you. Parent carers have talked about feeling a number of reactions, including:

- surprise
- anger
- confusion
- fear
- sadness
- comfort

- relief
- denial
- shock
- disbelief

You may feel one or many of these reactions or emotions strongly. Sometimes you may jump from one to another.

*“I never thought for a minute that she might be deaf. I felt so guilty that I might have caused it.”* Parent

*“At the initial diagnosis I had a terrible fear of feeling powerless. Sadness lingers, yet since the diagnosis we’ve grown stronger as a family and are committed to ensuring only the best for our child.”* Parent

Having a deaf child may mean that you have some extra things to learn about, but do not worry if you have no experience of deafness. There will be plenty of opportunities for you to find out what you need to know.

Learning to accept your child’s deafness is a process that you will go through at your own pace. For some people this process is quick; for others it takes longer. Many parent carers say acceptance is a continuing process. Whatever you are feeling is normal – there is no right or wrong way to react.

As well as accepting your child’s deafness, you need to accept that life for the whole family has changed. If your child has had or continues to have other health problems or **additional needs**, their deafness may not feel like your main priority.

*“After a short period, I accepted the hearing loss pretty well. I think the deafness was easier to accept for two reasons: we knew it was a very real possibility due to the meningitis and he was so ill he almost did not survive.”* Parent

Gathering information and meeting other parent carers can help to take some of the mystery and fear out of deafness and having a deaf child. It is important that you do these things when you feel ready. Parent carers say that it can be invaluable meeting other families of deaf children. It gives you an opportunity to see how others have coped and to meet older deaf children.

*“One of the best things for us was when we joined a parents’ support group. It was such a relief to be able to talk to people who understood what we were going through. Even more important was to be able to see deaf kids older than our daughter – we were amazed to see just how normal they were. We knew then she was going to be OK.”* Parent

Local groups that have been set up by parent carers of deaf children can also provide opportunities for families to come together at organised events and meetings. **NDCS** can

give you details of local deaf children's groups around the UK and other events where you can meet other families with deaf children.

## Telling others about your child's differences

Many parent carers say that they began to feel more comfortable with their child's deafness when they understood the effect it would have on their child and the family. Get the whole family involved with your child. Brothers and sisters, aunts and uncles, and grandparents and cousins can all play a big part in helping a deaf child to be included fully into family and community life.

Your family and friends can also be an important source of support for you and your child. They may offer to babysit for you, spend time with you and your child, or listen to you when you need to talk.

However, telling family and friends can be very hard. Only you know when and how it is best to tell other people. For some parent carers, explaining to family members can be an even bigger challenge than understanding the situation themselves.

You may need to give your family and friends who are not familiar with deafness some information about how to support you. For example, if grandparents are babysitting they need to know how to communicate effectively with your child. This can mean that they start to understand more about the effect your child's deafness has on you, your child and your family. It can also help your child to feel that they are a full part of the family.

*"I talked to [my family] about his hearing loss and how to communicate with him. For example, don't shout across a noisy room and expect him to respond. I told them to go over to him and communicate face to face. Deaf children learn visually. They need to see your face. Don't get upset if he doesn't respond. You need to check if he understands and allow him to respond. I think educating them is the key – but don't overwhelm them with the small details. Tell them what your child needs from them." Parent*

*"Having a deaf granddaughter has been one of the most rewarding and challenging experiences of my life. I always wanted to be a grandparent, but I was in no way prepared for having a grandchild who is deaf. Initially I felt out of my depth and unsure how to support my daughter and son-in-law. Now I know more, I feel confident and determined to be there for my granddaughter – after all, I'm her grandma." Parent*

## Siblings

It is important that brothers and sisters feel included in your deaf child's life, as their sibling's deafness will affect them too, even if they are not deaf themselves. There is no right or wrong way of telling your other children; each family will have its own way of communicating.

Siblings and other relatives of deaf children can experience different emotions. At times they may enjoy being with their deaf brother or sister; at other times they may find it

frustrating and difficult. Good **communication** will help them to understand each other, resolve issues and express emotions.

Young children are constantly learning about language and communication, and usually find it easier than adults to pick up new ways of communicating. If you involve your other children in the things you do with your deaf child, you can help everyone to understand that they are a full part of the family.

*“We encouraged [his brother and sister] from the very beginning. We showed them the communication skills we used with him. And we made sure that they talked to him, even when it was easier and faster to communicate through one of us.”* Parent

The extra work of communicating with a deaf child can mean that hearing siblings are given more responsibility at home than deaf children. Some parent carers of deaf children say that they more often ask hearing siblings to do tasks because it can be harder to explain tasks to a deaf child. This can be difficult for young children to understand.

It is important that your children can show you their feelings, even when those feelings are hard to accept. Some parent carers may find it difficult to talk to their hearing children about deafness so they use different ways to bring it into conversation, including stories and books, facial expressions, games and activities.

*“We went to the local library and found a book that was a story of a mouse who was deaf. We read the book together and I explained the mouse was like his sister as she can’t hear very well.”* Parent

Having a deaf sibling can be a positive experience for a child. It can allow them to have a positive attitude towards people’s differences.

*“I really like learning to lip-read and helping other people understand what it is like having a deaf sister; they find it fascinating. I can now lip-read other people’s conversations, which is great fun.”* Sibling

*“If I didn’t have a deaf sister life would be pretty normal, but life goes on in a different direction now.”* Sibling

## Early relationships and bonding

Some parent carers’ fears of not being able to communicate with their deaf baby can affect their early relationship. Remember, your baby’s deafness is normal to your baby – it is those around your baby who have to learn new things. Keep communicating with your child in every way that you can and they will reward and guide you with their responses.

*“We were so worried as we had never thought about communication with our other kids – it just happened. It was at a Family Weekend, we were asked to think about all the times we communicate with Josie in a day and the list was endless! That’s when we began to relax and think, ‘We can do this.’”* Parent

Encourage family and friends to relate to your child and try not to be too judgemental about how they do it. Everyone will have different ways of making connections and your role is to support and guide if needed.

## Deafness

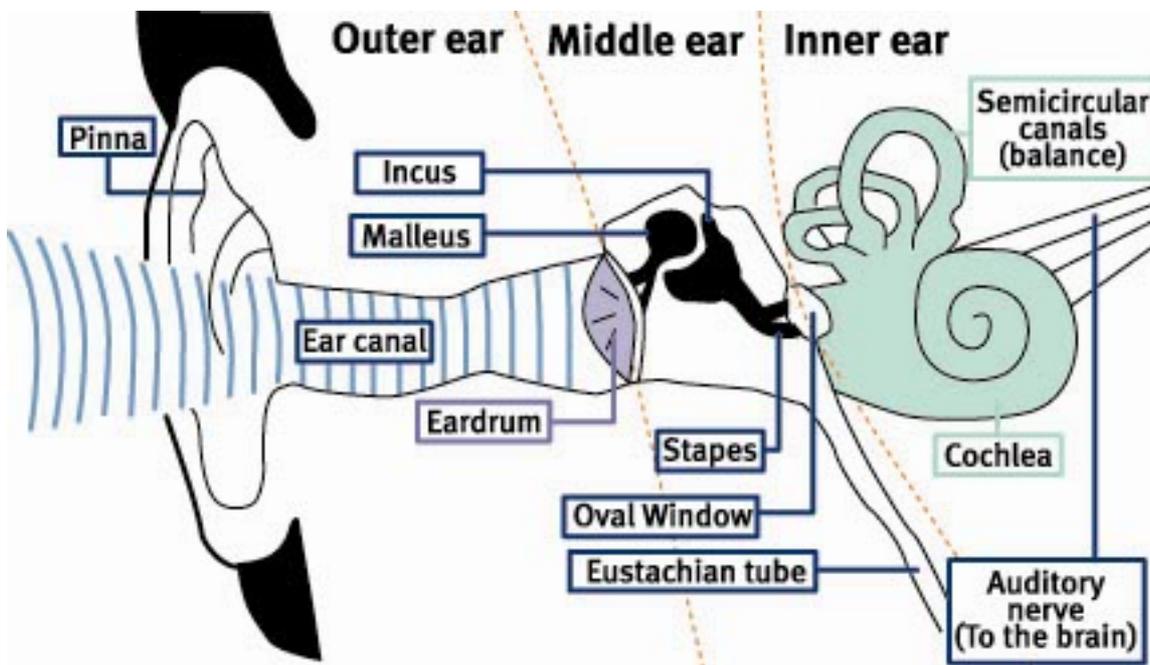
When your child is identified as deaf, you may be given lots of information about your child's deafness. This section explains some of the words and phrases you may come across.

### The ear

The ear has two main functions:

- It receives sound and converts it into signals that the brain can understand.
- It helps us to balance.

### Diagram of the ear



The ear is the first part of the hearing system. The pinna (the outside part of the ear) catches sound waves and directs them down the ear canal. The waves then cause the eardrum to vibrate. These vibrations are passed across the middle ear by three tiny bones: the malleus, incus and stapes (sometimes called the hammer, anvil and stirrup, together known as the ossicles). The bones increase the strength of the vibrations before they pass through the oval window into the cochlea.

The cochlea looks like a snail's shell. It is filled with fluid and contains thousands of tiny sound-sensitive cells called hair cells. The vibrations entering the cochlea cause the fluid and hair cells to move, like seaweed on the seabed when waves pass over it. As the hair cells move, they create a small electrical charge or signal. The auditory nerve carries these signals to the brain where they are understood as sound.

For an ear to work fully and allow us to pick up sound, all of these parts must work well. Deafness happens when one or more parts of the system are not working effectively.

## Balance

The brain uses information from the eyes (what we see), our body (what we feel) and the inner ear to help us balance. The semicircular canals in the inner ear are three tubes, filled with liquid and movement-sensitive hair cells. As we move, the fluid moves. This creates signals that are sent to the brain about balance.

When the organ of balance does not work properly, balance problems can occur (vestibular hypofunction). Sometimes the vestibular system and the cochlea have been affected by the same problem so deafness and balance problems can occur together. However, this is not always the case and many deaf children have excellent balance.

For more information about balance see the **NDCS** fact sheet *Balance and balance disorders*.

## Audiology

**Audiology** is the medical term for the study and measurement of hearing and deafness. The **audiology** department will usually be part of a hospital or local health clinic. The staff will measure your child's hearing, give you information about deafness, fit **hearing aids** if your child needs them and monitor their progress using them. If necessary, your child's **audiologist** will also refer you to other **practitioners** who can help, such as a **Teacher of the Deaf** and a **speech and language therapist**.

## Types and levels of deafness

To describe your child's deafness accurately your child's **audiologist** will carry out hearing tests suitable for your child's age and stage of development. The results of the hearing tests will tell you:

- the type of deafness
- the **level of deafness**
- which frequencies of sound are affected
- whether your child is deaf in both ears (**bilateral deafness**) or in one ear (**unilateral deafness**)
- whether the deafness is similar in both ears (**symmetrical deafness**) or different in each ear (**asymmetrical deafness**)

Deafness can happen at any age. Some children are born deaf and sometimes deafness develops during early childhood or later, during adolescence.

## Types of deafness

### Conductive deafness

**Conductive deafness** means that sound cannot pass efficiently through the outer and middle ear to the cochlea and auditory nerve. One cause of conductive deafness happens when a child is born without an outer ear.

The most common type of conductive deafness in children is a temporary condition called **glue ear** (or otitis media) – a build-up of fluid in the middle ear. It affects about one in five preschool children at any time. For most children, glue ear clears up by itself and does not need treatment. For some children with long-term or severe glue ear, **hearing aids** may be provided, or the child may be offered surgery to insert grommets into the eardrums. Grommets are tiny plastic tubes that allow air to circulate in the middle ear and help to prevent fluid from building up.

For more information about **glue ear** see the **NDCS** leaflet *Glue ear: a guide for parents* and fact sheet *Treatments for glue ear*.

### Sensori-neural (or nerve) deafness

**Sensori-neural (or nerve) deafness** means there is a fault in the inner ear (usually because the hair cells in the cochlea are not working properly) or auditory (hearing) nerve. **Sensori-neural deafness** is permanent.

There are many reasons why a child can have sensori-neural deafness at birth or develop it early in life. These include genetic factors, complications at birth, premature birth, infections caught during pregnancy and childhood illnesses, such as measles, mumps or meningitis.

It is not always possible to identify the reason. You will be offered tests that can help find the reason for your child's deafness. For more information on the medical tests used to help identify the cause of permanent deafness see the **NDCS** resources *Understanding your child's hearing tests* and *Genetic counselling*.

### Mixed deafness

Children who have **sensori-neural deafness** can also have **conductive deafness**, such as glue ear. This is called **mixed deafness**.

## Levels of deafness

The level of your child's deafness can be described in two ways: as a decibel (dB) hearing level; or as mild, moderate, severe or profound deafness.

Understanding these ways of describing your child's deafness can help you to explain it to others. If your child's deafness is described to you as a percentage, for example, 60%

deaf, you should ask for more information as this is not normally a useful way to describe deafness.

The table below shows the terms used to describe **levels of deafness** and the decibel levels that they refer to:

<b>Level of deafness</b>	<b>Hearing level in dB (loudness)</b>
Mild	20-40
Moderate	41-70
Severe	71-95
Profound	95+

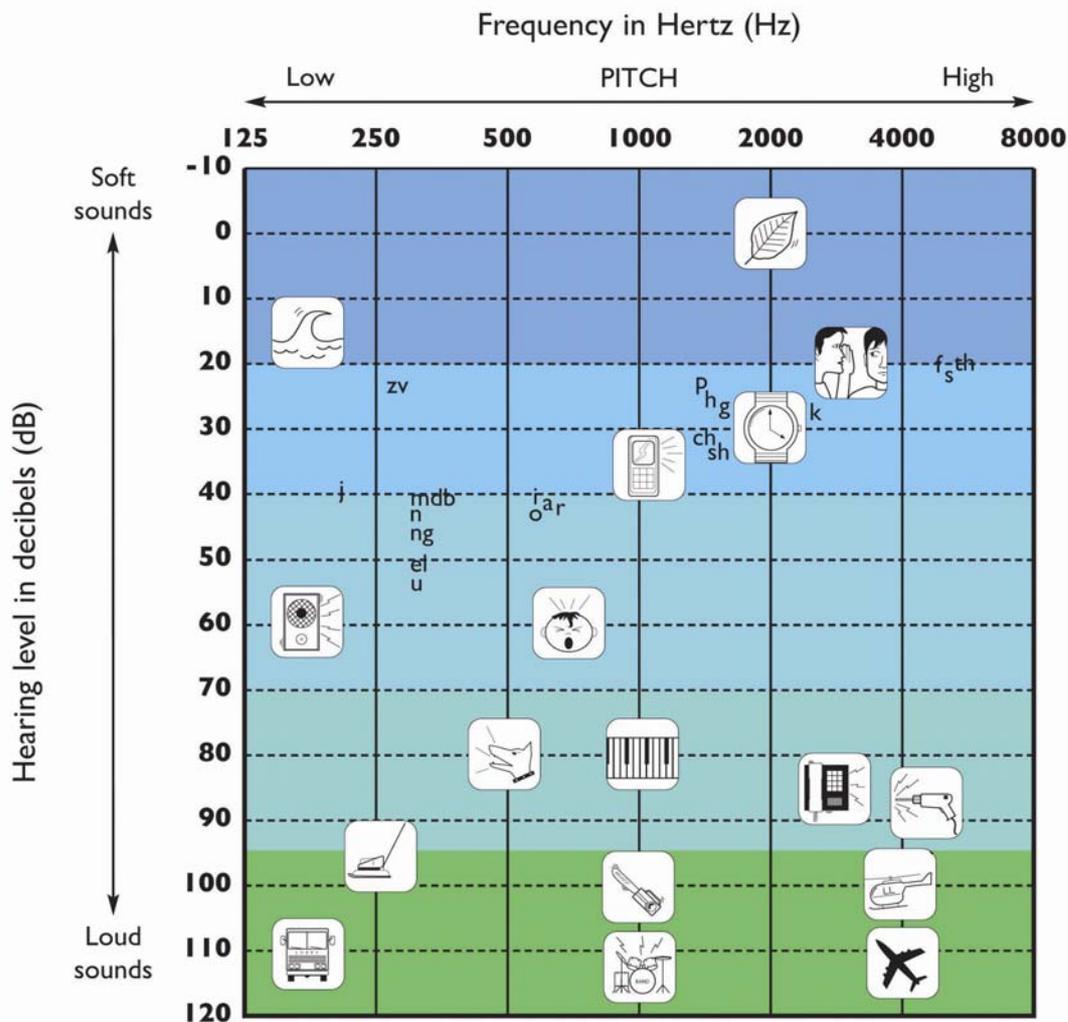
The level of deafness is calculated by establishing the average hearing loss in your child's better ear. Other descriptions may also be used to describe your child's deafness. These descriptions are based on the shape or configuration of the test results on the **audiogram**. For example, a hearing loss may be described as 'sloping', which is when some sounds are heard much better than others.

Any hearing that a deaf child has is described as **residual hearing**. Your child's **audiologist** will explain the results of your child's hearing tests. They will be able to explain which sounds your child can hear and which sounds they may find difficult to hear. If your child has recently been identified as deaf, the **audiologist** may need to do more tests before they can tell you this. If you are not sure about any of the information you have been given, you can go back and ask them to explain.

## **Frequency and hearing levels**

All sounds are made up of different frequencies. The frequency of a sound affects the pitch that it is heard at – the high notes on the right side of a piano keyboard are examples of high-frequency sounds. It is possible to be deaf at the same level across all frequencies, or to have different hearing levels at different frequencies.

Frequency is measured in hertz (Hz). When hearing test results are plotted on an audiogram, the low frequencies on the left to the high frequencies on the right are marked along the top of the audiogram. If your child has difficulty hearing sounds at higher frequencies they may be described as having high-frequency deafness. If they have difficulty hearing sounds at low frequencies they may be described as having low-frequency deafness.



Speech is made up of a range of frequencies, so it is important to consider frequency when thinking about a child's ability to hear speech sounds. A good example of this is the word moose. 'M' is a low-frequency sound, 'oo' is a middle-frequency sound and 's' is a high-frequency sound. To hear the word completely, a child must have appropriate levels of hearing at low, middle and high frequencies.

Your child's **audiologist** and **Teacher of the Deaf** can give you information about the frequencies affected by your child's deafness.

For more information on the ear and hearing, and the hearing tests that can be carried out to check your child's hearing, see the **NDCS** resource *Understanding your child's hearing tests*.

## What does deafness mean for my child?

The ways that individual children cope with their deafness vary greatly. The issues for a young baby will be very different from those of a teenager.

Deafness from birth or deafness that develops in the early years can prevent speech and language developing in the usual ways, which has an effect on other areas of children's development. However, with the right support from the start, deaf children can achieve on a par with their hearing peers, not only educationally, but also in terms of well-being and self-esteem.

When deafness develops for the first time in an older child or teenager, they may need extra help to find new ways of communicating and need support with accepting their deafness.

Later sections of this resource provide more information about some of the issues your child will face, such as **communication**, using **hearing aids/cochlear implants**, support at school and so on.

## Additional needs

Some deaf children are born with or develop other needs as well as their deafness, such as vision impairment, or learning or physical impairments. The impact of other additional needs on a deaf child can vary hugely. For more information about other **additional needs** see the **NDCS** publication *Deaf children with additional needs* and **NDCS** publications on specific conditions. At the end of this resource, the chapter on **Useful organisations and websites** sets out other organisations that may be able to provide further information on additional needs.

If you have any questions about your child's deafness or to order any of the publications referred to in this section, you can also contact the **NDCS** freephone helpline on 0808 8008880 (voice and text), or e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

## Early years

### Getting started

#### Being together

*“Looking back, some of the best times I had with my son when he was young was during our ‘together time’. I used to make time every day for just the two of us. We used to play a game or just chat about what we had done that day. Although some days it wasn’t easy to find the time, as I used to work, it was worth it.”* Parent

Parent carers often feel guilty because they cannot spend as much time as they would like with their child. Make space each day for some time together when you are free from distractions, you are not feeling rushed and your child is not tired.

#### Building relationships

At first, the direct family will be the main people in your child’s life, but it is worth encouraging wider family and friends to get to know your deaf child. This lets your child begin to explore the wider world and helps other people to begin to understand and learn about your child. Let people develop their own relationship with your child and they will gain confidence in each other.

*“My Mum developed a very special relationship with Molly – they tell me now that they used to dance around Granny’s house banging drums, or just stroll round her garden naming plants or watching the birds.”* Parent

Encourage people to communicate directly with your child when appropriate. It is tempting to jump in and speak for them, but that can make your child feel helpless and prevent relationships developing. If your child is joining a playgroup or local children’s club, you can visit beforehand and give the leaders some tips on supporting your child.

**NDCS** has a range of deaf awareness resources that you can share with family members and others to pick up basic **communication** tips. This, and all other **NDCS** resources referred to in this chapter, can be ordered from the **NDCS** freephone helpline on 0808 8008880 (voice and text) or by emailing [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

#### Understanding your child’s behaviour

Children’s behaviour can vary from child to child and from day to day. This is as true for deaf children as it is for hearing children.

It is important that your child can communicate their changing emotions to you so that you can understand their behaviour. This can sometimes be a challenge for some deaf children. Parent carers have suggested a variety of ways of helping their child express their emotions, such as:

- connecting with emotions through stories and books
- using facial expressions and gestures
- including **emotional vocabulary** when developing language

*"Acknowledging his feelings and letting him know that they are normal helps when he's emotional. Also, simply cuddles and telling him how much he is loved."* Parent

*"We make simple little finger puppets with scraps of material and then draw different faces on each finger, all showing different emotions. When he holds a finger up, we try to copy the emotion, like sad, happy, angry – it always ends up with giggles!"* Parent

Expectations for your child's behaviour should be the same as for any other child. However, it is important to remember that your child may mishear or misunderstand instructions, which can be a reason for not doing what they're told. Try to make sure that your child is clear about how they should behave and the consequences for misbehaviour. If you need to discipline your child, make sure that your child understands the reason for this.

### **Interacting and communicating**

Developing good **communication** skills is vital to all children and their families. These skills allow a child to learn from others and influence the world around them. This is an essential part of their emotional, personal and social development.

If your child is still a baby, communication will involve using your face, voice and body to show love and let your baby know you are there. If your child is older, you will need to think about the ways your family communicates to make sure they are fully involved. There are simple things you can do to ensure easy communication, such as making sure you get your child's attention before communicating with them, facing your child when you are speaking or signing, etc. For more information, see the **NDCS** resource *Communicating with your deaf child*.

How easily a child can naturally develop good language and communication skills depends on the quality of the language and communication environment. In other words, for children to develop a language well, they need to be surrounded by capable users of that language who take every opportunity to communicate with them. For families that speak English as an additional language, it may be more appropriate to communicate in their own language.

After finding out that their baby is deaf, parent carers will meet many **practitioners** who give advice and support, especially about how to encourage communication development. Practitioners may have different opinions about what is 'the best way' of communicating and strong beliefs about the different approaches or methods of communication. This may mean that they say one is better than another.

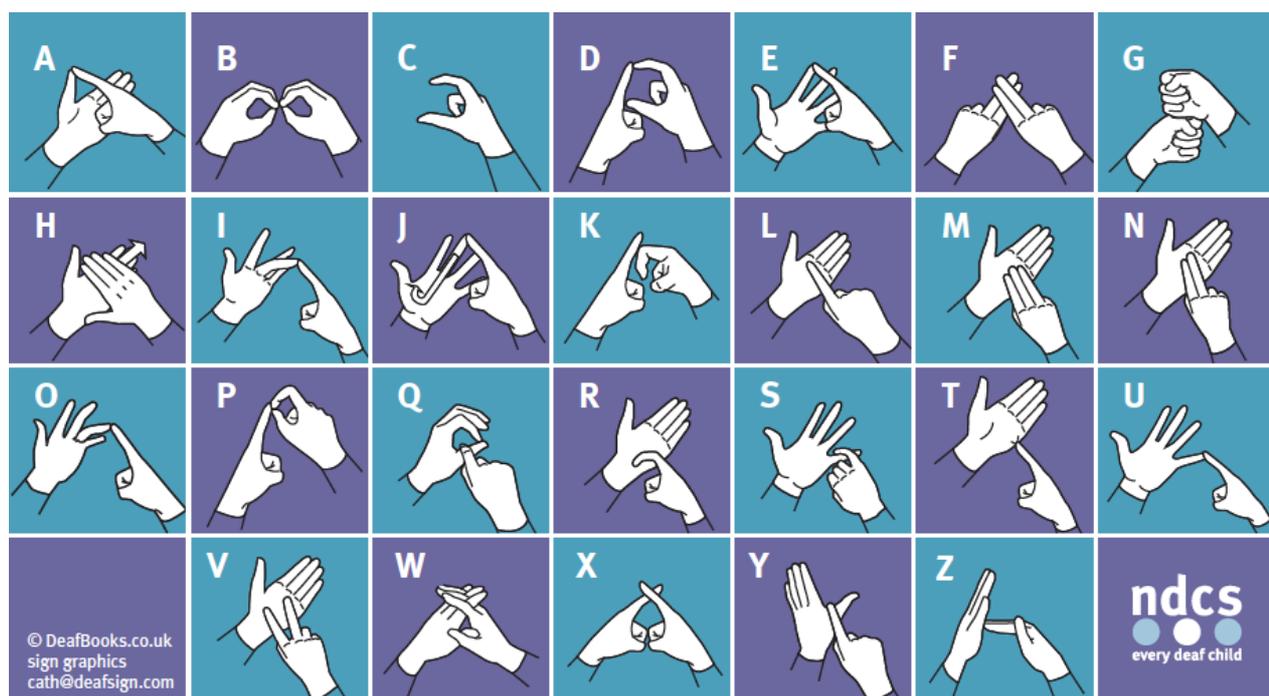
In fact, there is no one way that works best for all deaf children and all families. Sometimes, different approaches work well at different times for the same child and family. It is important to remember that there are no wrong choices and the right choices are those that work best for your child and your family.

The main communication approaches that deaf children and their families use fall into three broad areas:

- **Auditory-oral approaches** – These use **residual hearing** to develop listening and speaking skills.
- **Sign bilingualism** – This uses sign language as the child's first language, with speech learned as a second language. This approach is based on the belief that deaf children need a visual language to have full access to language learning, education, information and the world around them, and to create a strong, positive deaf identity and make social relationships. **British Sign Language (BSL)** is the main sign language used across the UK. It is a language in its own right with its own grammar and linguistic rules.
- **Total communication** – This involves using a variety of methods flexibly, such as signing, speech and hearing, **fingerspelling**, gesture, facial expressions and **lip-reading**, in the combination that works best for the deaf child (how total communication is developed and used varies, but it is based on the principle that deaf children can learn to communicate by using any ways that they are able to).

There are other ways of developing and supporting communication with deaf children, which may be part of another approach or fit into total communication. These include cued speech, **lip-reading**, **fingerspelling** and other methods of sign support. For children with **additional needs**, there are some other techniques, adaptations and/or systems to support language and communication development.

## Signing alphabet



It is important to remember that good **communication** is more than a method or approach – it is about meaningful interactions between people. Everyday life and activities help you to develop and reinforce language and communication skills, and support your child's social and emotional development, whatever method of communication you use.

In the very early months, children do not need a specific communication 'method'. As you care for and play with your baby, and respond to their communication attempts, you will be naturally supporting their communication and language development. By making the most of every technique – visual (looking), tactile (touching) and auditory (hearing) – you will be keeping your options open.

As your baby develops, you will be able to check how effective your communication choices have been in helping them to learn language and to communicate. You can talk to family members and **practitioners** to help you decide whether it is still the right choice. You can also ask for support from practitioners in developing your own communication skills, where appropriate. For example, your local authority may provide courses for families to learn sign language. NDCS has also developed a free, practical and interactive website to help families with deaf children up to the age of five learn basic British Sign Language (BSL) together, available at [www.familysignlanguage.org.uk](http://www.familysignlanguage.org.uk). A separate example comes from the Cued Speech Association who have developed a free online training resource for parents to learn how to use 'cued' speech to support their child's understanding of spoken language, available at [www.learntocue.co.uk](http://www.learntocue.co.uk).

Some choices may work better than others in some settings, so it is important to be flexible about communication strategies. For example, in quiet conditions your child may access spoken communication with ease, but in more noisy or busy environments it may

be more helpful to use a range of strategies that make it easier for your child to communicate.

Support for all communication choices is not always readily available everywhere or available at no cost. If your preferred choice is not routinely supported by local services in your area, talk to your local practitioners who can help you get the support and information you need. Remember, it is your child's needs that should guide your choice.

For more information about **communication** see the **NDCS** resource *Communicating with your deaf child*.

### **Working with practitioners**

There is a range of services, **practitioners** and groups that can offer you and your child support, and some of the main practitioners you may come into contact with are described below. For information on other practitioners, see the **NDCS** fact sheet *People you may meet*.

It is important to remember that you will know your child better than any practitioner who works with them. The role of all the practitioners listed below should be to support you and your child, and to encourage them to develop as fully as possible.

If English is not your first language and you are not fluent in English, you should request an interpreter when working with practitioners to ensure that you fully understand them.

### ***Audiology department***

The **audiology** department is part of the health service. It can help by:

- carrying out hearing tests
- telling you about the type and level of hearing loss your child has
- assessing if **hearing aids** will be useful and, if so, supplying them
- referring you to other health practitioners, such as **speech and language therapists** or specialist **hearing implant centres**, where other hearing equipment may benefit your child
- providing earmoulds for your child's **hearing aids**
- helping you maintain your child's hearing aids
- monitoring your child's hearing levels
- referring you to educational support services for deaf children
- working with other practitioners, such as ear, nose and throat (ENT) doctors and **Teachers of the Deaf**, to provide support to you and your child

### ***Speech and language therapists***

**Speech and language therapists** offer support and advice to parent carers of children with any type of **communication** problem, including deaf children. They help children to develop their communication skills in sign language or speech.

For more information see the **NDCS** resource *Deaf children and speech and language therapy*.

### ***Hearing-impaired service (also known as sensory support service)***

The hearing-impaired service is normally provided by the **local authority**, which has responsibility for education. It provides specialist services for deaf children and their parent carers in the child's home, at nurseries, playgroups in children's centres or in school. It also offers advice, support and training to nurseries, playgroups, schools and colleges teaching deaf children and young people. The hearing-impaired service can provide information and support on:

- deafness in children and its impact on learning
- language and communication
- other support services
- your child's **hearing aids** or **cochlear implants**
- issues relating to being the parent carer of a deaf child
- your child's education
- applying for a place in nurseries, playgroups, children's centres and schools

### ***Teachers of the Deaf***

**Teachers of the Deaf** often play an important role in helping parent carers to support their deaf child. They are qualified teachers who have taken further mandatory training specifically to teach deaf children. They provide specialist support to deaf children, their parents, carers, family, teachers and to other **practitioners** who are involved with a deaf child's education. Many **Teachers of the Deaf** teach and work with deaf children directly.

### ***Social services***

Social services are part of your **local authority**. As a parent carer of a deaf child, you can ask them to assess the needs of you and your child. Social services in your area may provide:

- equipment for your child
- sign language classes (sometimes called language aid schemes)
- information on useful local organisations
- play schemes and play care services
- parent carer groups
- advice on welfare and financial **benefits**, and access to social housing
- cultural forms of support

### ***Additional needs***

If your child has more than one **additional need**, you may be in contact with other practitioners and services. Even when deaf children have severe and complex additional

needs, it is still important that their deafness needs are met and that you receive support from all relevant practitioners. If deafness is not noticed or managed it can cause or contribute to speech or language delays and difficulties learning, reading and communicating with others, as well as lead to behaviour that is challenging for others. This means that it can accentuate the effects of other impairments that a deaf child has.

## General information

### Everyday life and making sense of the world

Babies first develop emotionally and physically by having all their needs met. A newborn baby cannot bear to wait and wants you to respond very quickly. Security comes from not having to wait too long to be comforted, fed or cuddled.

As babies get older and start to develop some independence, their social and emotional development happens as a result of their everyday experiences. They learn to take turns, communicate, gain some control of conversations and realise that they can influence what happens and make sense of the wider world.

Later, when a child is older but cannot quite manage to do what they are trying to do or express how they feel, they will become frustrated. They may also find it harder to make sense of everyday life and realise what is happening. It is important to develop your child's **emotional vocabulary**, which helps them say how they are feeling. This can stop frustration building up.

You can use emotional vocabulary from the beginning. For example, when your baby is hot and flustered you might say or sign, "Are you feeling grumpy?" When Mum or Dad comes home from work and the baby smiles, Grandma might say and/or sign, "You're really happy to see Mummy/Daddy, aren't you?"

You can find more detailed information on this in chapter three of the **NDCS** resource *Communicating with your deaf child*.

### Equipment and aids

#### **Hearing aids**

**Hearing aids** help your child to hear as much as possible with the hearing they have. The type of hearing aid offered will depend on the type and level of your child's hearing loss.

Most hearing aids work by making the sounds going into the ear louder. They come in various shapes and sizes. Hearing aids will be programmed to closely match your child's hearing levels at the different frequencies.

The most common type of hearing aid is a behind-the-ear (BTE) hearing aid, which sits behind the ear and is connected by a tube to an earmould in the ear. The earmould allows the sound to enter the ear in the most efficient way. There are also hearing aids that work using vibration, called bone-conduction hearing aids. Your child's **audiologist** will be able to give you more information on the most suitable type for your child.

If your child would benefit from hearing aids you will be able to get them from the NHS through your local **audiology** service. For more information, see the **NDCS** resource *Hearing aids: information for families*.

### **Hearing aid safety**

Babies and young children often try to put things in their mouths, and **hearing aids** are no exception. It is important to be aware of this because the parts of a hearing aid can be a choking hazard.

One especially dangerous part is the battery, which a child could potentially swallow. If this happens, contact your nearest hospital casualty department immediately and tell them what type of battery has been swallowed and how long ago. Take a similar battery and the packaging with you to the hospital so staff can identify the type of battery and decide what action to take.

Young children can also put batteries up their nose or in their ears, where they can occasionally remain unnoticed until they start to cause ulcers or other problems.

It is important to keep an eye on the location of batteries at all times. They should be disposed of carefully. Some audiology departments will ask you to return used NHS batteries. If you put them back into their original packaging after use, you will be able to see if any are missing.

Try not to let young children see batteries being changed so that they do not know that the battery compartment opens. Most NHS hearing aids have, or can be fitted with, a childproof battery compartment. Ask your child's audiologist for further information.

### **Cochlear implants**

A **cochlear implant** is an electronic device that stimulates hearing in children and adults who are severely or profoundly deaf and who cannot hear the full range of speech sounds with the most powerful hearing aids. An operation is needed to fit Cochlear implants. After the fitting, a lot of support is provided to help children use their implant as effectively as possible. The **NDCS** resource *Cochlear implants: a guide for families* provides clear, balanced and accurate information about cochlear implants.

### **Other equipment**

A wide range of useful equipment is available to deaf children, some of it from social services. Your local education authority may provide equipment that your child needs for their education. Children's needs change as they grow, so investigate what is suitable at different ages.

The **NDCS** publication *Technology at home* gives guidance on equipment and explains how you can get the equipment your deaf child needs.

### **Developing the senses**

The ear is fully formed before birth and hearing babies will have had exposure to sound even before they are born. However, the ear is just the first part of the auditory (hearing) pathway.

The auditory pathways are made up of nerves that carry sound from the ears to the brain. Neural connections in the pathway and brain develop in response to auditory stimuli (sound). The brain organises itself around the information that it receives.

This development of neural connections is known as neuroplasticity. We know that the brain changes throughout people's lives, but the most rapid changes in brain development happen in very early childhood. Neuroplasticity is greatest in the first three-and-a-half years of a child's life. **Hearing aids** and **cochlear implants** are usually offered as early as possible so that babies and young children have the opportunity to access sound and develop critical auditory pathways. You can support your child's listening development by:

- providing an environment that includes lots of meaningful language for your child to learn from
- using their hearing aids and/or cochlear implants consistently
- improving the listening environment and reducing background noise as much as possible

Babies often go through stages when they remove their hearing aids themselves. Usually, this is just a developmental stage and they are doing it 'because they can', until other things occupy their attention more. If your baby is doing this, try to avoid it becoming a game where they attract your attention each time it happens. You may need to take the hearing aids away for a short time before trying them again while they are distracted by something else. If taking out their hearing aid is an ongoing problem, discuss it with your **audiologist** or **Teacher of the Deaf** and monitor progress.

### **Playing**

All children like to play and have fun. Playing with your child helps them to develop a wide range of skills and can play a very important part in developing your child's language and **communication**. Very young babies play too, but on a more basic level. This can include simple games like peek-a-boo or games played while feeding. Play does not have to be different because your child is deaf.

The main point of playtime is to have fun. It can also help children to get to know more about themselves and the world around them. Activities that use toys, books and other materials help children to express themselves and improve their vocabulary. They can also help them become more confident with language, however they decide to communicate. If your child uses sign language, playtime can be a good opportunity to introduce new signs or concepts.

Some toys have been designed specifically for deaf children. These are fun to play with and have an extra purpose, such as helping to develop speech, language and communication.

For more information see the **NDCS** fact sheet *Playtime and deaf children* and watch the NDCS DVD *All together: having a deaf child in the family*, which provides activity ideas for

the whole family. NDCS has videos on making safe play areas, creating a sensory experience and making safe toys at:

[www.ndcs.org.uk/family\\_support/how\\_ndcs\\_can\\_help/our\\_films\\_and\\_podcasts/sensory\\_experience.html](http://www.ndcs.org.uk/family_support/how_ndcs_can_help/our_films_and_podcasts/sensory_experience.html).

## Sleep

Getting children into sleep routines can be difficult for all parent carers. Parent carers of deaf children often say that the things that can work with hearing children, such as music and story tapes, do not work so well with children with hearing loss.

If your baby uses **hearing aids/cochlear implants**, some may not like the quiet when the aids are taken out at night. If the room is dark they may also become scared and disorientated.

Leaving a hall light on can help. Rotating light mobiles that make patterns on the wall or ceiling, or glow-in-the-dark stickers can also help by focusing the baby's attention elsewhere.

You can help your child to feel safe by leaving a bit of your clothing with them so they are aware of your familiar smell. It is also good to tell your child that you are leaving the room so they do not get worried when they realise you have gone.

## Home environment

Try to make your home the best environment for communication possible: soft furnishings help to cut down excess vibrations, thus reducing echoes; good lighting means your child can see you communicating; and avoiding too much visual clutter will help focus your child's attention.

Involve your child in everyday activities like cooking, cleaning and doing the shopping, and maintain conversation throughout these routines to introduce new language and vocabulary.

When the television is on, switch on the **subtitles** so your child starts to realise that the writing carries information.

## Financial support

You may be able to claim **benefits** as a parent carer of a deaf child. The main benefit is Disability Living Allowance (DLA).

DLA is a benefit for people who have a long-term illness or **additional need**. It provides extra money for people who need:

- help with personal care (the care component)
- help with walking (the mobility component)

DLA is a tax-free benefit that is not means tested. This means that it does not matter how much money you have and it will not reduce any other benefits you get. In some circumstances, DLA can increase the amount of other benefits you are entitled to.

If your child is awarded DLA, you may be eligible to claim Carer's Allowance. Carer's Allowance provides support for people looking after someone who is disabled.

For more information, see the **NDCS** publications *Disability Living Allowance for deaf children and young people* and *Disability Living Allowance: a guide to filling in the claim forms for deaf children* (guides for three different age groups).

Changes are sometimes made to the benefits system. For more information on any changes or on other benefits that you may be entitled to, visit [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits).

There are several financial grants available for deaf children and their families. For more information on the organisations that provide financial grants, contact the **NDCS** freephone helpline on 0808 8008880 (voice and text) or e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

## Meeting others

### Parent carer and toddler groups for deaf children

Many parent carers say that feeling isolated and not knowing what the future holds is frightening at the start. It is often when they meet other families with deaf children that they begin to feel more confident.

*"Meeting other families...it was the best thing. To be able to talk to parents with similar experiences, who understand your hopes and fears, who can give you some tips and listen to yours – it was like we'd joined a real world again. None of these families were the same as ours and that didn't matter. They had all chosen different ways of doing things and that was reassuring too – there wasn't just one way to go."* Parent

**NDCS** runs Family Weekends for families with newly identified deaf children so they can meet and support each other. Many families then go on to join or set up their own parent carer and toddler groups. Some support each other on the internet through Facebook, Twitter and NDCS's online discussion forum Parent Place.

### Support groups

Support groups help families in the same area meet and support each other by sharing information and experiences. Try to find out if there are local support groups near you. These may be set up by services working with deaf children or by parent carers. Some groups organise events and activities, others may just be an occasional catch-up at someone's house.

*“I get inspiration from meeting the other parents, particularly the ones with older children, so I know what the future looks like.”* Parent

For more information about local groups for deaf children and their families visit the **NDCS** website [www.ndcs.org.uk/localgroups](http://www.ndcs.org.uk/localgroups).

Some areas also have Parent Carer Forums. These generally do not have a deaf focus but, in many areas, they can be a way of influencing and shaping local services. For more information visit [www.nnpcof.org.uk](http://www.nnpcof.org.uk).

## **Deaf adults**

*“Our first encounter [with an adult who was deaf] was very reassuring; it gave me hope for the future. My aspirations for my child could still be fulfilled even though she had this disability.”* Parent

Deaf adults and young people can provide an insight into the experience of growing up being deaf and, as users of local services, be a useful source of information. Your local services should be able to put you in contact with other deaf adults and young people who can support you, share their experiences and answer any questions about what it is like to be deaf. Deaf adults and young people may also be able to tell you about any local deaf clubs and social networks in your community.

## **Going out with your child**

Many people have not met a deaf person before and sometimes they may stare at your child, which can be uncomfortable. Different families deal with it in different ways.

*“Many people just need someone to shed light on something they are embarrassed or afraid to ask about. It’s important to keep a cool head and be prepared to speak openly and honestly about your child’s deafness.”* Parent

*“My son loves the attention and will make sure that when people are staring at him, he starts signing and playing with his implant.”* Parent

*“I used to get really upset when people would stop and stare – I’d look back at them angrily. Now I smile sweetly, which usually makes them look away quickly or come over and talk to us. Most people are just intrigued and want to find out more, so I try to educate them about deafness and sign language.”* Parent

## Education – early years

Deaf children often need support to be able to take full advantage of education. If your child needs extra help or different help from other children of the same age, you may begin to hear people talking about their additional needs. If your child requires additional support it is important for you to have an opportunity to influence what they receive.

All children are different and have different abilities and support needs. Your child's abilities and needs may be very different from another child with a similar **level of deafness**. However, it is important to remember that deafness is not a learning disability. Have high expectations of your child. As long as deaf children have the right support, they should benefit from the same opportunities as every other child and thrive.

Shortly after your child's hearing loss has been identified, you are likely to be contacted by a **Teacher of the Deaf** who will probably stay in contact with you through the early years of your child's life. The support that you, your family and your child receive depends on how much extra help your child needs. Teachers of the Deaf usually visit families in their home. You and the Teacher will decide together how often this will happen.

When the **Teacher of the Deaf** visits you at home, they will be able to advise you on:

- early language and communication development
- making the most of play
- developing social skills
- encouraging your child to wear their **hearing aids**
- working with your **audiology** clinic to make sure your child is getting the most benefit from their hearing aids
- creating the best listening environment for your child
- general child development issues
- school placement options
- advising anyone who is also caring for your child during the day
- other useful contacts and voluntary organisations

Many Teachers of the Deaf also work with and teach deaf children directly.

If a number of different **practitioners** from education, health or social care services are working with you and your child, you may be given a key worker. This is someone who maintains regular contact with your family and makes sure that:

- you have all the information you need
- services are well coordinated
- information about your child is shared efficiently with everyone who is working with your family

Because Teachers of the Deaf visit families in the home regularly, they often take on the role of key worker, but it could be a person from another service.

## Choosing an early years setting

Early years providers include childminders, playgroups, nurseries, children's centres, and nursery classes in primary schools. It is important for you to find out from the **local authority** what type of provision could best meet your child's needs and what additional support is available to ensure your child fully participates and makes progress. Your child's **Teacher of the Deaf** or your local authority's Parent Partnership Service should be able to advise you on the local options for your child.

The **NDCS** fact sheet *Which school for your deaf child?* contains information on what you might want to consider when choosing an educational setting for your child. Though this fact sheet is mainly about schools, many of the suggested questions are equally applicable to parent carers choosing an early years setting.

## Starting early years education

Whether your child attends a playgroup, childminder, nursery, children's centre or a nursery class there are a number of things you can do to ensure your child makes a good start:

- Get to know the staff in the setting and tell them about your child's needs. Ask what you can do at home to prepare for and support what your child is learning.
- Arrange opportunities for your child to visit and get to know the setting.
- Discuss with your child's **Teacher of the Deaf** how your child will be supported. The **Teacher of the Deaf** can advise the staff on how they can meet your child's needs and what changes may need to be made. This may include advice on how to create a good listening environment, how to teach your child and develop their language, and how to ensure other children in the early years setting are deaf-aware and understand what deafness means.

Keep in regular contact with staff at the setting and your child's **Teacher of the Deaf**. They should give you regular updates on your child's progress and tell you how you can support your child's learning so that it is enjoyable and fun.

Your early years setting may also have a special educational needs coordinator (SENCO) and an equalities named coordinator (ENCO), who are tasked with meeting SEN and equalities planning and needs. It is worthwhile meeting with these staff to review your child's whole needs over and above their deafness.

## School years

### Getting started

By the time their child begins formal education, some parent carers will have known that their child is deaf for some time and have built up strong relationships with local support networks and **practitioners**.

Other parent carers may have children whose deafness has only just been identified. If you have just found out that your child is deaf, a lot of the information in the **In the Beginning** and the **Early Years** chapters will be relevant, even if your child is starting school. These contain information on issues such as **communication** and outline the different reactions that parent carers have to finding out their child is deaf.

If your child is older when they develop deafness, they may have strong feelings about what has happened. It is important that they have an opportunity to understand how their deafness will affect their life and to talk about how they are feeling. They may need extra help to find new ways of communicating with you and may take a long time to accept their deafness.

If you have a good understanding of your child's deafness, it will help you when you are explaining it to them (if they are old enough) or to other people involved with them.

It is important that you have access to the full range of information so that you can make the right choices for you and your family. Your local education and **audiology** services can help you to find information, as can the **NDCS** freephone helpline, 0808 8008880 (voice and text), or you can e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

If your child has other **additional needs**, you may already be in touch with other practitioners and organisations that can provide information and support.

### Going with the flow

#### Playing

All young children like to play and have fun. Playing with your child involves lots of communication and helps them to continue to develop a wide range of skills. Play does not have to be different because your child is deaf, but some games that are reliant on hearing may need to be adapted to ensure your child can participate. For example, you could switch the lights on and off when playing musical chairs.

The main point of playtime is to have fun. It can also help children to get to know more about themselves and the world around them. Activities that use age-appropriate toys, books and other materials help children to express themselves and improve their vocabulary and language development. They can also help them become more confident with language, however they communicate.

Some toys have been designed specifically for deaf children. These are fun to play with and have an extra purpose, such as helping to develop speech and language.

Your child might also attend a before-school or after-school scheme, playscheme or open access play facility and these provisions are expected to adapt their play environment and programmes to allow for access and inclusion for children with additional needs, including deaf children.

For more information see the **NDCS** fact sheet *Playtime and deaf children* and watch the NDCS DVD *All together: having a deaf child in the family*, which provides activity ideas for the whole family. NDCS has videos on making safe play areas, creating a sensory experience and making safe toys at:

[www.ndcs.org.uk/family\\_support/how\\_ndcs\\_can\\_help/our\\_films\\_and\\_podcasts/sensory\\_experience.html](http://www.ndcs.org.uk/family_support/how_ndcs_can_help/our_films_and_podcasts/sensory_experience.html).

### **Sleep**

Getting children into sleep routines can be difficult for all parent carers, particularly those with younger deaf children. Parent carers of deaf children often say that the things that can work with hearing children, such as music and story tapes, do not work so well with children with hearing loss.

If your child uses **hearing aids/cochlear implants**, some may not like the quiet when the aids are taken out at night. If the room is also dark they may become scared and disorientated.

Leaving a hall light on can help and many parent carers recommend using a small nightlight. Rotating light mobiles that make patterns on the wall or ceiling and glow-in-the-dark stickers can also help by focusing the child's attention elsewhere.

### **Equipment and aids**

#### ***Hearing aids***

**Hearing aids** help your child to hear as much as possible with the hearing they have. The type of hearing aid offered will depend on the type and level of your child's hearing loss.

Most hearing aids work by making the sounds going into the ear louder. They come in various shapes and sizes. Hearing aids will be programmed to closely match your child's hearing levels at the different frequencies.

The most common type is called a behind-the-ear (BTE) hearing aid, which sits behind the ear and is connected by a tube to an earmould in the ear. The earmould allows the sound to enter the ear in the most efficient way. There are also hearing aids that work using vibration, called bone-conduction hearing aids. Your child's **audiologist** will be able to give you more information on the most suitable type for your child.

If your child would benefit from hearing aids you will be able to get them from the NHS through your local **audiology** service. For more information see the **NDCS** resource *Hearing aids: information for families*.

### **Cochlear implants**

A **cochlear implant** is an electronic device that stimulates hearing in children and adults who are severely or profoundly deaf and who get little or no benefit from hearing aids. An operation is needed to fit cochlear implants. After fitting, a lot of support is provided to help children use their implant as effectively as possible. The NDCS resource *Cochlear implants: a guide for families* provides information about cochlear implants.

### **Radio aids**

A **radio aid** is usually used in school. It consists of a transmitter worn by a teacher, for example, and a receiver, worn by the child. The radio aid works by making the sound the child needs to hear (the teacher's voice) clearer in relation to other unwanted noise. Radio aids can also be helpful in the home. For more information on radio aids see the NDCS publication *Radio aids: an introductory guide*.

### **Other equipment**

Making the home environment practical and accessible for deaf young people has become easier with new technology. This technology also helps to promote independence. Some specialist equipment can be provided by local education or social care services. Your **Teacher of the Deaf** may be able to provide further advice. Some of the types of equipment are listed here:

- **Alerting products** – These signal that something is happening, such as a doorbell or fire alarm ringing, by using flashing lights or vibrations. Pagers can connect to different pieces of equipment and vibrate and flash when they are activated.
- **Communication products** – These include amplified and hearing aid-compatible telephones, accessories that use Bluetooth to connect to phones and text services to help your child communicate with the outside world.
- **Entertainment** – There are many products and devices that give access to popular equipment like iPods, games consoles, computers and televisions. These include **subtitles**, which are words that appear on the screen and show, as closely as possible, what the programme's characters, presenters, etc., are saying. There are also some TV programmes presented in **British Sign Language** or with sign support. Making sure that deaf children and deaf young people have access to the media, television and the internet like their peers is important for their social well-being and education. Webcams can keep deaf children and young people in touch with their friends.

For more information see the **NDCS** publications *Technology at home* and *Technology impact report*.

The NDCS Technology Test Drive service loans out equipment to families of deaf children and deaf young people. For more information about this service and products for deaf children and deaf young people visit [www.ndcs.org.uk/technology](http://www.ndcs.org.uk/technology).

### Personal care

As your deaf child grows older, start involving them in caring for the equipment and technology that they use, such as putting on and taking off **hearing aids** or **cochlear implants**, checking that batteries are working, and so on. This will encourage them to take ownership of their aids and feel more confident in using them.

### Financial support

You may be able to claim **benefits** as a parent carer of a deaf child. The main benefit is Disability Living Allowance (DLA).

DLA is a benefit for people who have a long-term illness or **additional need**. It provides extra money for people who need:

- help with personal care (the care component)
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There are several financial grants available for deaf children and their families. To find out more information on the organisations that provide financial grants contact the NDCS freephone helpline, 0808 8008880 (voice and text), or visit [www.ndcs.org.uk](http://www.ndcs.org.uk).

## Choices and challenges

### Communication

In the [Getting Started](#) section of the [Early Years](#) chapter, we set out some of the issues facing parent carers of deaf children in choosing the right **communication** approach for their child.

As your child gets older, you will be able to check how effective your communication choices have been in helping them to learn language and to communicate. Some choices may work better than others in some settings, so it is important to be flexible about communication strategies. For example, in quiet conditions your child may access spoken communication with ease, but in more noisy or busy environments it may be more helpful to use a range of strategies that make it easier for your child to access communication.

### Friendships

You may be worried that your deaf child will have difficulty mixing with other children and might be isolated. Other parent carers have stressed the importance of out-of-school activities, hobbies and socialising with other children in the family. It is important that your child can mix with both deaf and hearing children.

Activities outside of school time help children to socialise and develop skills and interests. Contact local or school clubs that run activities your child is interested in, such as sport, culturally specific clubs, art or drama, and encourage your child to try them out. Your child may feel more confident about joining in if they invite a friend to go with them.

Organisations, including **NDCS**, run a range of events to give deaf children opportunities to meet other deaf children, whilst having fun and developing skills. NDCS also has a range of resources to support mainstream youth organisations in making their activities accessible for deaf children.

### Coping with differences

Some deaf young people experience high levels of frustration or get angry due to a lack of communication and information, because they are seen as different or unable to express emotions. They also experience the usual frustrations that all children have, particularly in the teenage years. You might not always understand their emotional reactions, but they need to be able to express their own emotions to come to terms with them. Accepting your child's feelings is key to showing that you accept and value them as a person.

*“At times over the years my child has been very upset about their deafness. I think it is important for parents to allow these feelings without getting caught up in trying to ‘fix it’ or make compensations.”* Parent

Encourage your child to accept their deafness by supporting them to get to know other deaf children and making sure they are exposed to positive deaf role models. Deaf role

models can help deaf children understand their feelings, learn about what it is like to grow up deaf in a hearing world and develop their confidence.

Most children and young people are keen to fit in with their peers, especially during their teenage years. This is also when deaf young people tend to become more aware of the differences between themselves and their hearing peers.

Be aware of possible issues around **emotional well-being**. Deaf young people are more likely to suffer from poor emotional health and well-being than hearing children and young people due to communication difficulties and the resulting feelings of isolation and difference. Some children may be teased and picked on because of their deafness or other differences. Ensure your child knows they can tell you if they are worried or are having problems at school, and make sure they feel that they can raise problems with certain members of staff if they want to.

### **Developing independence**

Many parent carers of deaf children and young people say that it is important to resist the urge to be overprotective. Deaf children need to develop their independence in the same ways hearing children do.

All children and young people face challenges as they grow up. Learning from experience, being resilient and bouncing back can help to develop your child's confidence. You can help build your child's confidence through support and encouragement, which sometimes includes learning to let go. It is important to be aware of suitable levels of independence for your child.

From getting up in the morning to communicating with people who know little about deafness, it is important that deaf young people 'manage' their deafness. For example, if your child tells someone that they are deaf and explains how they communicate, they will feel in control. This will increase their confidence when meeting new people. Help your child to feel confident enough to tell people about their deafness and their communication needs. You could practise this at home so that your child will feel comfortable doing it in public.

## Education – school years

Deaf children and young people often need support to be able to take full advantage of education. If your child needs extra help or different help from other children and young people of the same age, you may begin to hear people talking about their **special educational needs** (SEN). If your child requires additional support it is important for you to have an opportunity to influence what they get.

All children and young people are different and have different abilities and support needs. Your child's abilities and needs may be very different from another child or young person with a similar **level of deafness**. However, it is important to remember that deafness is not a learning disability. Have high expectations of your child. As long as deaf children have the right support, they should benefit from the same opportunities as every other child or young person and thrive.

### Choosing a school

School should be a time of fun, learning and development. Your child can develop their independence and understanding of the world, make new friends and pursue new activities and interests. Choosing a school where your child will be happy and have the best chances to learn and develop is therefore very important. Whichever school you choose for your child, it is important that it will meet their needs and is suitable for their age, skills and ability. There are several types of secondary school that your child could go to, including:

- **mainstream schools** (which includes all academies and free schools)
- **mainstream schools with specialist provision** for meeting the needs of deaf children (sometimes known as specialist resource provision or a 'unit' for deaf or hearing impaired children)
- independent or private mainstream schools
- special schools for the deaf
- special schools for children with a range of other significant learning needs

To find out more about the different types of schools see:

- the **NDCS** fact sheet *Different types of school for deaf children in England*
- the NDCS resources *Starting school* and *Starting secondary school*
- the Department for Education website [www.education.gov.uk](http://www.education.gov.uk)
- the Government website [www.gov.uk](http://www.gov.uk)

Here are some tips to find out more about the schools in your local area:

- Search for information on the internet. For example, the Ofsted website ([www.ofsted.gov.uk](http://www.ofsted.gov.uk)) enables you to search for all schools within a certain distance of your home.

- Ask other parent carers about schools in your area.
- Ask your child's **Teacher of the Deaf** and other **practitioners** who know your child about local schools.

If your child is moving to secondary school, you may find that your primary school has a relationship with a local secondary school, acting as a 'feeder' to the other.

Once you have a list of schools, it is a good idea to research those that interest you in more depth:

- Ask the school for a prospectus. This should give general information about the school and information on its policies, such as equal opportunities, children's rights, **special educational needs**, religion and bullying.
- Read the latest school Ofsted inspection report. This is often on the school's website or the Ofsted website ([www.ofsted.gov.uk](http://www.ofsted.gov.uk)).

Visit the schools you are interested in. Many schools will have open evenings or open days where parent carers can look round the school and ask questions. Visiting a school can give you a more complete picture of what it is like and how your child will fit in. The **NDCS** fact sheet *Which school for your deaf child?* is a checklist of useful questions that you could ask the school.

Your child's feelings about a school are important, so take them to have a look and meet the staff, too. After the visit, ask your child what they like or do not like about the school. Think about how your child will form effective relationships with other children at the school. Some deaf children may benefit from being in a school with other deaf children to avoid feeling isolated.

Where schools have specialist provision for deaf children, they may follow a particular **communication** approach. You will need to consider how this matches your child's own communication preferences and how the school will support your child's communication skills.

Once you have an idea of the most appropriate school for your child, you may find it helpful to make an appointment with the school's **special educational needs coordinator (SENCO)** to discuss your child's needs and how the school will meet them. The school might also have in place an equalities named coordinator (ENCO) who is tasked with meeting children's holistic identity needs over and above their disability. The SENCO and ENCO often work together to meet common goals.

It is important to start preparing early in deciding which school you would prefer. Find out from your **local authority** what the deadline is for giving your preference so that you have time to visit some schools before you choose. There are a number of services funded by the local authority that may be able to advise you. These include the Parent Partnership Service, the school admission service, the **Teacher of the Deaf** or, if your child has a **statement of special educational needs**, the statutory assessment / statementing service.

You will need to tell your **local authority** which school you would prefer your child to go to. They will then tell you whether your child has been given a place in your preferred school. If your child is offered a place in a different school, they should explain how to appeal against this decision.

### **Starting primary school: transition from early years**

Once you have chosen a primary school, you should start preparing your child for school life. When your child starts school, a **Teacher of the Deaf** can give the school information about deafness and help your child settle in. This might include teaching deaf awareness to the teachers, other staff and children at your child's school. Extra help in the classroom is often given by a **Teacher of the Deaf** who visits the school or a teaching assistant who can help ensure your child can participate in lessons and make progress.

The school day is often very different from a day at home or at nursery. These changes may be a surprise to your deaf child unless you make them aware of the routines they are likely to expect in school. You could try some of the following ideas to prepare your child for school life:

- Use reference cards with pictures or photographs of things that they may not be familiar with at school (for example, a desk, a whiteboard, the dinner hall and activities). Look at these pictures with your child, explain them and answer any questions. Once your child has started school, they could use the pictures to tell you what they have been doing and whom they have been working with.
- Take your child to playgroup, nursery, a children's centre or clubs and play schemes to help them get used to being with large numbers of children and different adults, and to develop their social skills.
- Use books and toys during play to help your child to express what they are feeling, improve their vocabulary and gain more confidence.
- Visit the school with your child before they start.

For more information see the following **NDCS** publications:

- *Starting school*
- *What are you feeling? A guide to teaching emotional literacy in the classroom*
- *What are you feeling? A guide to developing emotional vocabulary for children who are deaf and may have learning difficulties*

### **Starting secondary school: transition from primary school**

For ideas on how to support your child and the school with moving to secondary school see the NDCS resource *Starting secondary school*. It includes information on:

- travelling to school
- helping your child get used to the new school, school rules and school staff

- giving information to school staff, including background information about your child's home language, ethnicity, religion or beliefs alongside your child's deafness
- preparing your child for the variety of lessons
- helping your child prepare for more homework on a wider variety of subjects, and for meeting more teachers
- preparing for exams and assessments
- extracurricular activities
- dealing with bullying or discrimination
- developing independence
- how you can get involved with your child's secondary school

Again, your child's **Teacher of the Deaf** can give the school information about deafness and help your child settle in. This might include teaching deaf awareness to the teachers, other staff and children at your child's school.

### **Home/school communication**

It is important to keep in contact with your child's school. School staff can give you advice on what to do at home to support your child's learning, to ensure that it is enjoyable, stress-free and consistent with what they are learning at school. The school can give you regular, up-to-date and accessible information about your child's:

- progress against targets and what is being done about any difficulties they may be experiencing
- participation in school life, including developing social skills and friendships

Communicating everyday information between school and home can be hard for deaf children who may miss or misunderstand verbal information or instructions. To help, the school can:

- use a home/school notebook that is kept in the child's school bag to provide an important link between teachers and parent carers
- establish a regular way for staff to update parent carers, for example, by email, meetings or by phone
- send text messages to ask parent carers to look out for information coming home or when a pre-planned activity is coming up

It is important that the school discusses with you when and how you will receive this information and how often you will receive it.

### **Working with practitioners**

There is a range of services, **practitioners** and groups that can offer you and your child support during the school years. It is important to remember that you will know your child better than any practitioner who works with you. The role of all practitioners should be to

support you and your child, and to encourage them to develop as fully as possible. The people you meet may include:

- a **Teacher of the Deaf**
- a special educational needs coordinator (SENCO)
- an educational psychologist
- an audiologist
- a speech and language therapist
- a deaf instructor/British Sign Language tutor
- a communication support worker
- a learning support assistant/teaching assistant
- an equality named coordinator (ENCO)

Some of these practitioners' roles have been explained in the [Getting started](#) section in the [Early years](#) chapter. For more detailed information on these roles and other practitioners, see the [NDCS](#) fact sheet *People you may meet*.

### **What if things aren't working?**

Your child's **special educational needs coordinator (SENCO)** will arrange support in school, with assistance from your child's **Teacher of the Deaf**. If you have concerns about how your child is doing in school you can ask to speak to your child's teacher or **Teacher of the Deaf**, who will then liaise with the school's SENCO as needed.

How much support your child gets in school will depend on what needs to be done to ensure they can fully participate in lessons and the life of the school. Some deaf children can make progress with little extra help. Others need great levels of support and the **local authority** may need to establish the type and level of special educational provision they will receive and write a **statement of special educational needs (SEN)**. A statement of SEN is a legal document that explains your child's needs and the help they should have. It is checked every year to make sure that the extra support still meets your child's needs.

For more information about what to do if your child still has difficulties, contact the NDCS helpline or your local Parent Partnership Service provided by the local authority.

At the time of writing, the Government is currently proposing a range of changes to the SEN framework. It is expected that these changes will take effect from September 2014. For information about how these changes might affect your child, contact NDCS.

### **The Equality Act**

The Equality Act 2010 says that schools must make 'reasonable adjustments' for people with additional needs. They must make sure that disabled children are not at a substantial disadvantage compared with non-disabled children.

The Equality Act is anticipatory, which means that schools need to think about the adjustments they might need to make even if they do not currently have any children with additional needs. Reasonable adjustments for deaf students might include communication support, such as a **sign language interpreter**. They could also mean making information sources, such as leaflets, more accessible.

For more information, contact **NDCS** or the Equality and Human Rights Commission at [www.equalityhumanrights.com](http://www.equalityhumanrights.com).

## Meeting others

### Parent carer support groups

Many parent carers say that feeling isolated and not knowing what the future holds is frightening. It is often when they meet other families with deaf children and deaf young people that they begin to feel more confident.

**NDCS** runs Family Weekends where families with deaf children and young people can meet each other. Many families join or set up their own parent and toddler groups. Some support each other on the internet through Facebook, Twitter and NDCS's online discussion forum Parent Place.

Support groups help families in the same area meet and support each other by sharing information and experiences. Try to find out if there are local support groups in your area. These may be set up by services working with deaf children or by parent carers. Some groups organise events and activities, others may just be an occasional catch-up at someone's house.

For more information about local groups for deaf children and their families, visit the **NDCS** website [www.ndcs.org.uk/localgroups](http://www.ndcs.org.uk/localgroups).

### Deaf adults

Deaf adults and young people can provide an insight into the experience of growing up being deaf and, as users of local services, be a useful source of information. Your local services should be able to put you in contact with other deaf adults and young people who can support you, share their experiences and answer any questions about what it is like to be deaf. Deaf adults and young people may also be able to tell you about any local deaf clubs and social networks in your community.

### Short breaks

Sometimes deaf children might benefit from a short break from the family, so that they can explore new things and meet new people; likewise, families with a deaf child may benefit from having a short break. This may be away from your child or a situation where someone else provides activities or care for your child. Taking a break from caring for your child is not an admission of failure or a way of saying you do not care. Keeping going is easier if you have had some time to do the things you cannot do while looking after your child.

Many people take breaks by asking other members of the family, friends or neighbours to take charge occasionally. Your child's GP or social worker may also be able to arrange a short break, or you may be able to arrange and pay for it privately.

The Contact a Family website has more information on short breaks at [www.cafamily.org.uk/know-your-rights/short-breaks](http://www.cafamily.org.uk/know-your-rights/short-breaks). NDCS also runs a range of events for deaf children.

To order any of the NDCS resources referred to in this chapter, contact the NDCS freephone helpline on 0808 8008880 (voice and text), or e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

## Into adulthood

### Getting started

This section helps you think about how to support your deaf child in their journey towards adulthood. Deaf young people have the same aspirations as all young people. They want to:

- succeed in education
- get a job
- become independent

Their deafness should not stop them achieving these things, but it may provide challenges for them along the way, which will also be shared by parent carers and others who support them. These challenges might come in many different forms:

- **Deaf young people are young people as well as deaf** – Deaf young people will have the same experiences as other young people. They will want to make new friends, build relationships and develop their own identities. Some deaf young people might experience extra pressures related to their deafness and some may need support to build up their confidence to handle such challenges.
- **Changes to services** – Sometimes the services that deaf children and young people receive, such as in **audiology** and education, and financial **benefits** change once they reach a certain age. This might mean a different way of doing things.
- **Becoming an adult** – Deaf young people face new challenges as they become young adults. They have to adapt to the different demands at college and in the workplace. They will also need to make sure they know about, and assert, their rights to services and support.

### Acquired, progressive or late onset/late identification of deafness

If your child or young person has **acquired deafness/late onset deafness** (becoming deaf after birth) or **progressive deafness** (hearing that gets worse over time) or they have just been identified, you could read earlier sections in this resource for background information, such as **At the beginning** and **What does deafness mean for my child?** This section will still be useful as your child will need your support on their journey towards independence, but if you need more information on supporting a child or young person who is still learning about their deafness contact the **NDCS** freephone helpline on 0808 8008880 (voice and text) or e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

## Thinking about the future

### Helping young people choose what they want from life

This section provides information about the options your child, as a young adult, is likely to have. Find out about your local services to get an idea of what is on offer and how well it meets your child's needs. Building a picture of your local area can help you support your child to make decisions as they approach adulthood.

If your child is in year eight, you should help them think about their options for year nine when they begin their GCSEs or similar courses. You might also want to think about what will happen when your child turns 16 because the choices they make now, such as which courses they decide to take, will make a difference later.

From year nine onwards, your child's school or **local authority** should help you and your child plan for the future. This planning process should ensure that their choices now, or their plans for when they are 16, are supported by the right educational and audiological support. Some of the things to consider as part of this planning process are:

- your child's hopes and aspirations for the future
- what you as a parent carer expect and hope for, and what you feel you can contribute to your child's plan
- who will be responsible for providing future support and services
- any further information that your child needs to make an informed choice
- what other local support there might be to help your child make decisions
- whether or not there are special issues relating to how your child will access services when they reach 16
- the support your child might need to access the curriculum
- where your child intends to continue their education when they reach 16

This process might be described by some of the **practitioners** who support your child as 'transition planning'. In successful transition planning the child's views are at the heart of the plan. Some young people may not have the confidence to get their point across so it is important that parent carers ensure their child is heard. They need to know themselves to make choices, so help them think about:

- what they like doing
- what they are good at
- what they would like to do in the future

Once your child has a clearer idea of what they would like to do in the future, encourage them to consider some specific questions about how to achieve their goals:

- What would I like to learn?
- Do I need to do a certain course to get the job that I want?
- What qualifications do I need to do a certain course?

- How do I access the course?
- How is the course assessed? (For example, what type of exams are involved?)
- What qualifications will it give me?
- How do I find out more about courses?

Have high expectations for your child's educational outcomes and future independence. This can give young people the confidence and the drive to achieve to the best of their ability and overcome any obstacles they may encounter.

Although this process of planning should begin as early as possible, final decisions do not have to be made straight away. Like many young people, they might still be undecided, even in year 11. There are lots of opportunities to get more information in year 11, such as college open days and link courses. Try to make sure that such opportunities are accessible to your child and that appropriate communication support is provided.

Sometimes there may be disagreements about your child's options. If the planning for their future has been done properly, these disagreements should become apparent as soon as possible and resolved through discussions with the **local authority** and/or relevant provider. However, sometimes it might be more difficult to come to an agreement. The NDCS freephone helpline can provide you with information about what to do if this happens. Call 0808 8008880 (voice and text), or e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk).

### **School/college options**

#### ***Choices at 16***

By 2015 all young people will stay in education and training until at least their 18<sup>th</sup> birthday. However, young people will still have a number of options when they reach 16.

Remember that the choices open to your child will depend on what is available in your area so do some local research. Do not be afraid to approach schools, training providers and colleges, and even employers, to find out more about the options. Try to find out if any existing schools, training providers and colleges already have good support available for deaf young people.

Choices should always be about what is best for the young person. However, sometimes this process will need to balance competing priorities. For example, some options might have a reputation for providing high-quality **communication** and educational support for young people, and a deaf peer group, but be unable to offer the particular course that is needed for your child to fulfil their ambitions.

Remember that education providers and others have legal duties to make reasonable adjustments to support deaf young people, though some may be better prepared to do so than others. They also have a duty to give regard to your child's other equalities needs, such as their religion or beliefs, gender, ethnicity, sexual orientation, etc. For more information on the types of support deaf young people can access and the legal backing for this, see the box below on communication support and the Equality Act 2010.

## Communication support and the Equality Act 2010

### *Communication support*

Different types of support are available to deaf young people in post-16 education settings and in employment. Deaf young people should talk to their **Teacher of the Deaf** or another adviser about which kind of support would suit their learning needs and **communication** best. Communication support that young people may be able to access includes:

- communication support workers (CSWs)
- note takers
- speech to text reporters (sometimes known as a palantypists)
- sign language interpreters
- lipspeakers

To find out more about these forms of communication support and how to access them see the **NDCS** fact sheet *Your deaf child from 16+: a guide to post-16 education in England, Wales and Northern Ireland* and *Your deaf child from 16+: a guide to post-16 education and training support in Scotland*.

### *The Equality Act*

The Equality Act 2010 states that education providers, service providers, employers and public bodies must make 'reasonable adjustments' for people with additional needs. They must make sure that disabled people are not at a substantial disadvantage compared with non-disabled people.

The Equality Act is anticipatory, which means that people need to think about the adjustments they might need to make even if they do not currently have any students with additional needs. Reasonable adjustments for deaf students might include communication support, such as a **sign language interpreter**. They could also mean making information sources, such as leaflets, more accessible.

Employers must also take action to stop discrimination under the Act. People are not allowed to discriminate, harass or victimise another person because they are disabled. There is also protection against discrimination for someone who is associated with the person who has a protected characteristic. This might be a parent carer.

Some of the choices that may be open to your child include the following:

- **Staying on in their current school** – Many young people will want to stay on at their current school if it has a sixth form. The school may offer a stable educational

and social environment, as well as the right options. Some schools have entry requirements to their sixth forms, such as a certain level of GCSE performance.

- **Going to a new school or sixth-form college** – Some young people will change schools at 16 if their school does not have a sixth form, or if other local schools or sixth-form colleges offer better provision or a better range of courses.
- **Going to a general further education (FE) college** – As well as ‘academic’ courses, FE colleges also provide vocational opportunities, including apprenticeships (see below). They often employ different teaching styles, with a greater emphasis on lectures, seminars and independent learning than sixth-form colleges.
- **Beginning an apprenticeship or joining a training provider** – An apprenticeship means learning skills in a particular industry by doing a job in that area, as well as completing a qualification. Some apprenticeships mean that young people are employed and paid. In some apprenticeships young people are not employed but spend more time in college. Both types include spending time in a relevant workplace learning new skills.
- **Starting a career** – Although by 2015 all young people will stay in education until their 18<sup>th</sup> birthday, they will still be able to work at 16 as long as their employers provide training as part of the job or allow time off for part-time study. You will find more information about employment below.
- **Going to a specialist college** – There are some colleges in England that cater specifically for deaf young people and others that cater for young people with **additional needs**, including deafness. Some young people take up residential placements at these colleges.

When your child makes choices at 16 it will be important that you continue to support them to think about the issues described earlier in the section [Helping young people choose what they want from life](#). There may also be more detailed things to think about for each option, such as the following:

- Does the option your child is considering provide high-quality support educationally?
- Does their choice get the right balance between the institution and the course? Where is it likely to lead them next?
- What is the quality of the institution in general (not just for deaf young people)? Do young people who go there do well?
- Have they considered transport to the various options?
- Do you need to think about your child’s social development and opportunities to meet other deaf young people?

To find out more about types of education providers and the process of transition see the **NDCS** fact sheets:

- *Your deaf child from 14+: a guide to transition in England, Wales and Northern Ireland*

- *Your deaf child from 16+: a guide to post-16 education and training in Scotland*
- *Access to apprenticeships*

At the time of writing, the Government is currently proposing a range of changes to the SEN framework. It is expected that these changes will take effect from September 2014. For information about how these changes might affect your child, contact NDCS.

### **Choices at 18**

At 16, most young people continue in some form of education and the choices they have at 18 are similar to those described above (except that schools only accept young people up to the age of 18).

It is important to note that when young people turn 18 they may have to pay for further education, though this will depend on different things, including their educational attainment levels. Your child will need to research different courses and discuss with colleges or other providers whether they will be required to pay fees. If they are, they will be able to get a loan (similar to the scheme for higher education) to pay these. To find out more, visit [www.gov.uk](http://www.gov.uk).

When young people reach 18 they also have the option to go to university. If your child is going to university, you need to think about the same things as when they were making choices at 16. However, going to university can also mean living away from home, which is a big step towards independence.

If they go to university, your child will be responsible for their own educational support. They may receive Disabled Students' Allowance, which provides money to pay for **communication** and other support.

#### **Applying for the Disabled Student Allowance (DSA)**

It is important that young people going to university arrange their support in advance. This means that when they arrive they can concentrate on settling in, enjoying themselves and keeping up with their studies. They should apply to Student Finance England for DSA. They can do this at the same time as making their online UCAS application by ticking the DSA box on their student loan application form.

Once they have applied, there will be some forms to fill in to provide evidence of their deafness. This will be followed by a 'needs assessment' in which an assessor sits down with them to discuss what support they need.

Once their DSA has been confirmed, they will receive advice on how to spend it. They should talk to the disability officer at their university or college to organise personal support, as there may be arrangements in place for deaf students.

The [Developing independence](#) section later on in this chapter is useful for parent carers who have a child going to university.

## Work options

Deaf young people have the same aspirations as other young people and there is no reason why they should not be able to fulfil these. Almost all careers should be open to deaf young people, apart from a small number of jobs for which there may be health and safety concerns, or where access to sound is a vital part of performing the tasks involved.

The Equality Act applies to employers and means they must make adjustments in the workplace for deaf people. This also applies to interviews and assessments that are part of the application process. Some deaf young people may need some support in preparing job applications and writing CVs.

It is important that deaf young people starting a career take responsibility for their own support. Their employer will not tell them what to do all of the time. Prepare your child for the world of work by encouraging them to use their initiative and take responsibility for their timekeeping, responsibilities and belongings. Work experience can provide a good opportunity to experience the wider world and contribute towards future work choices. Encourage your child to think widely and follow their interests.

### Access to Work

Access to Work is a government-funded scheme that provides advice and sometimes funding for people with additional needs to get support and equipment (including communication support) at work. Some employers may not know about the funding they can get from this scheme, so if your child might be eligible they should discuss this with their employer. For more information, visit

[www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)

## Living options

When your child is ready to leave home, you may feel a mixture of emotions. You might be proud that you have helped them to grow into a confident and independent adult.

However, it can also be an emotionally challenging time. If they are leaving home, then they have already achieved a degree of independence, which means they can be trusted to look after themselves and make sensible decisions. However, like any young person they will need support finding their first home and after they have moved in. The following organisations focus specifically on these areas:

- Shelter – [http://england.shelter.org.uk/get\\_advice/housing\\_advice\\_for\\_young\\_people](http://england.shelter.org.uk/get_advice/housing_advice_for_young_people)
- Leaving Home (resources, activities and practical information about leaving home) – [www.leavinghome.info](http://www.leavinghome.info)

## Other options

As your child is growing up, you might claim certain **benefits** on their behalf, which help towards costs related to deafness. When they reach 16 they will need to start taking responsibility for this. Some deaf young people will be eligible for Personal Independence Payment (PIP) benefits, which support disabled young people with the costs of their **additional needs**. To find out more about benefits for deaf young people, visit the **NDCS** website [www.ndcs.org.uk/benefits](http://www.ndcs.org.uk/benefits).

When your child is ready to leave home or has some financial independence, you can support them by making sure they have the skills to manage their own money. For some helpful tips, visit the Money Advice Service website [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk).

## Developing independence

### Everyday life

As your child becomes more independent, you may have new concerns about their safety, such as dealing with difficult situations when socialising. Discuss with your child what arrangements they can make to ensure they keep safe. For example, you could encourage them to carry a pen and paper and a personal alarm with them. You could also make sure they know how to contact the emergency and car breakdown services, and how to avoid confrontation.

Talk to them too about the possibility of being picked on because of their deafness and how they might challenge this and report it.

### Social activities

**Communication** difficulties can mean that deafness has an impact on your child's social experiences, for example, talking in groups and following fast-moving conversations. Encourage conversation and socialising, and suggest ways of initiating friendships. Encourage them to develop the confidence and skills to tell others that they are deaf and how to communicate with them.

If there are other deaf people at their college/training provider/workplace, encourage them to organise regular events, outings or meetings. This will help to stop them feeling isolated and help them to develop friendships and socialisation. Suggest that they get involved with the local deaf community by taking part in events and attending deaf clubs or other social networks.

### Personal care

Many deaf young people say that they missed or misunderstood information about personal care at school. You could discuss personal care issues with your child to make sure they have information around healthy eating, keeping their body fit, internet safety,

sexual relationships and the use and misuse of drugs. You should reiterate how to stay safe when out and about, including how to contact the emergency services.

Explain that first impressions count. Emphasise how important it is to keep their body and clothes clean and smart for interviews and work.

Be aware of possible issues around **emotional well-being**. Deaf young people are more likely to suffer from poor emotional health and well-being than hearing peers due to communication difficulties and the resulting feelings of isolation and difference. There may be times when your child needs extra support to help them accept their deafness, or deal with education worries, problems at home or work, or relationship difficulties. Ensure your child knows they can talk to you, or anyone else they feel comfortable with.

If your child feels they are suffering from stress or depression, they should visit their GP, who can refer them to agencies that offer help.

### **Growing pains**

Remember that your child will be going through the same 'growing pains' as other young people. They will be exploring their identity and starting to form close relationships with others. Some young people may also be exploring their cultural, sexuality, gender and religious identity or beliefs. Support them through this as you would any other child.

Some deaf young people experience high levels of frustration or get angry due to a lack of communication and information, because they are seen as different or unable to express emotions. Respect and accept your child's emotions, even if you do not understand or agree with them. Being able to express themselves and knowing that you value them will help them come to terms with their feelings. Remember, and remind them, that not all negative feelings will be related to their deafness.

Encourage your child to accept their deafness by showing them, and encouraging them to find, positive deaf role models. Encourage them to find out more about 'deaf history' and how deaf people in the past have overcome the challenges. Some of the resources, organisations and websites listed later can help deaf young people to explore these issues. Deaf peers and adults can boost a young person's confidence by helping them to understand their identity and resolve issues.

### **Asserting independence**

As your child becomes increasingly independent, it can be difficult to let go, especially if you are worried about how safe they are going to be. Allow them to make their own decisions about things that affect them, to make mistakes and, most importantly, to learn from them, while ensuring they know they have your support and guidance.

## The home environment

Making the home environment practical and accessible for deaf young people has become easier with new technology. While they were living with you, you probably made sure that your child had the right technology at home to know when someone was at the door or if the fire alarm was activated. It is important that when they leave home, you encourage and support them to take responsibility for this.

## Equipment and aids

If your child uses a **hearing aid** or **cochlear implant**, they will need to keep in touch with their local **audiology** clinic or cochlear implant centre for ongoing maintenance and to make sure they are using the best possible equipment.

Paediatric (children's) and adult audiology services are very different. Changing between them can also be different throughout England. When young people move to adult services they will need to take on more responsibility for their own health care. Ask your child's paediatric **audiologist** about how the change takes place in your area. If your child is moving town or city, they will need to find out about the audiology services in that area beforehand and make sure they have registered with the service.

Being independent at home and making social and educational improvements usually requires specialist equipment. Some of this can be provided by local services. Some of the types of equipment that deaf young people may find useful are listed here:

- **Alerting products** – These signal that something is happening, such as a doorbell or fire alarm ringing, by using flashing lights or vibrations. Pagers can connect to different pieces of equipment and vibrate and flash when they are activated.
- **Equipment to help with using the phone** – Some equipment has increased volume and different tones, or loops that work with hearing instruments on a 'T' setting.
- **Webcams** – If your child uses sign language these can help them to keep in touch with friends and family over the internet.
- **Equipment that can help with using audio equipment** – This often involves using Bluetooth to connect to iPods, MP3 players, portable games consoles and mobile phones, and can be used with a hearing instrument on the 'T' setting.
- **TV listening equipment** – This uses a loop around the room, radio or infrared signals.
- **Radio aids** – These are used in education to improve the sound quality coming from a teacher or lecturer. To find out more see the **NDCS** publication *Radio aids*.

Encourage your child to take responsibility for deciding which specialist equipment will be best for them as they get older.

The NDCS Technology Test Drive service loans out equipment to families with deaf children. For more information about this service and products for deaf young people, and the difference they can make, visit [www.ndcs.org.uk/technology](http://www.ndcs.org.uk/technology).

## Letting go

### Supporting choice and autonomy

By the time your child leaves school and enters adulthood, they should be taking responsibility for their belongings, timekeeping, appointments and so on. Checking that your child can do some small things can help with the 'letting go' process for parent carers. For example, make sure they know how to contact the emergency services, how to make an appointment at the doctors or **audiologist**, and that they can plan journeys on public transport and cope with any unexpected changes to their journey.

From getting up in the morning, to communicating with people who know little about deafness, it is important that deaf young people 'manage' their deafness. For example, if your child tells someone that they are deaf and explains how they communicate, they will feel in control. This will increase their confidence when meeting new people.

Make sure your child has ways to cope with challenges or disadvantages they may face. These might include having the confidence to ask people to speak more clearly or repeat things, being able to use technology, or finding out when subtitled films are on in the cinema.

### Developing self-awareness

Encouraging your child to accept that their deafness is a part of who they are is an important step in developing confidence. By valuing and respecting themselves they are sending out the message that they are worthy as individuals. Be inspired by the experiences of other deaf young people by meeting and talking with them. Suggest to your child that they meet and mix with other deaf young people. When someone feels OK about being deaf, they have reached the stage where they are positively acknowledging and accepting it. This process does not happen for all deaf young people and it may not happen until later in adulthood.

Your child may not understand why they are deaf and might not have asked you about it. Make sure they know the reason for their deafness, even if the answer is that no one knows. By understanding the reasons behind their deafness, they will feel more confident talking about it to other people, and dealing with any questions that may arise.

Whilst it is important that your child accepts their deafness, they also need to feel there is much more to them than their deafness. Encourage them to widen their horizons. It is important that they get involved with activities that they enjoy and find meaningful. This

could be joining a sports or drama club, a cultural support group or society, volunteering, or undertaking a course or training that will help them succeed in their chosen career path.

### **Supporting positive risk-taking**

As your child enters adulthood, they will experience new life challenges in work, college and relationships. Being resilient and having strategies for bouncing back from setbacks and taking the initiative are essential in developing their confidence to deal with these issues. Encourage them to recognise areas where they have felt vulnerable and what they did or could do in order to boost their confidence (and resilience) if it happens again.

Encourage your child to take positive risks in life. Even though something may seem scary or unachievable to them, the benefits and sense of achievement can be worth the risk. Help them to assess and manage risk in everyday life and apply this to other situations.

## Top tips

- There is no right or wrong way to feel or react when you discover your child is deaf. You will have your own way of accepting your child's deafness.
- Remember that you are not alone. There is a range of local services and voluntary organisations that can support you and your child, and your friends and family may want to help too. Find out what support is available in your area.
- Your deaf child is a child first and foremost – play and communicate with them as much as you would with any other child.
- Get the whole family involved. Make sure your child develops direct relationships with everyone in the family, including siblings and grandparents.
- Other parent carers of deaf children have faced the same challenges and had the same fears as you. When you are ready, take the opportunity to meet other families or to join local parent carer support groups.
- You will meet lots of **practitioners** – remember they are there to support you and your child, and to help you make the best decisions for your child. Do not be afraid to ask for more information if you have missed anything or to go back when you have had time to think.
- Language is the cornerstone to lifelong learning and effective **communication**. Good language skills will help your deaf child develop well socially, emotionally and educationally.
- There are many communication options open to your child and you will need to choose the right option for your child. The 'right choice' is the one that works best for your child and your family. This may change over time as your child learns and develops, and their needs change.
- Remember that deafness is not a learning disability. Deaf children have the same potential to attain and achieve as any other child given the right levels of support.
- As your child gets older, encourage them to accept their deafness and to be confident in recognising their own needs and telling others about them. Also, encourage and support your child to develop a strong identity not just as a deaf person, but in terms of their culture, ethnicity and so on.

## Who can help?

As previously listed in this resource, there are a range of **practitioners** who can help and support you and your child.

Many parent carers of deaf children also say that they value being able to meet and talk with other parent carers. Local groups that have been set up by parent carers of deaf children can also provide opportunities for families to come together at organised events and meetings. **NDCS** can give you details of local deaf children's and deaf young people's groups around the UK, and other events where you can meet parent carers and families with deaf children and deaf young people.

NDCS's Parent Place is an online discussion forum, at [www.ndcs.org.uk/parentplace](http://www.ndcs.org.uk/parentplace), where parent carers can share their experiences and ask questions.

There are also a range of organisations, including **NDCS**, which can help and support you and your child. Some organisations focus on a particular aspect or approach to deafness. These are listed in the [Useful organisations and websites](#) section later in this resource.

**NDCS** is the leading charity dedicated to creating a world without barriers for deaf children and young people.

**NDCS** membership is free of charge to all parents and carers of deaf children, and **practitioners** who work with deaf children and their families. **NDCS** members enjoy access to the membership areas of the website, our publications and services.

NDCS has a range of information resources covering the topics of **audiology** and childhood deafness, education, financial support, technology, family life and communication. To contact **NDCS**, call the freephone helpline on 0808 80008880 (voice and text), e-mail [helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk), visit [www.ndcs.org.uk/livechat](http://www.ndcs.org.uk/livechat) or [www.ndcs.org.uk](http://www.ndcs.org.uk).

If you prefer to speak a language other than English, you can call the **NDCS** freephone helpline and say the language of your choice and your phone number (in English). NDCS will call you back with an interpreter within a few minutes. NDCS also has information resources available in community languages at [www.ndcs.org.uk/bme](http://www.ndcs.org.uk/bme).

## Resources

### Action Deafness Books

Supplies books and other resources on deafness and deaf issues.

[www.actiondeafnessbooks.co.uk](http://www.actiondeafnessbooks.co.uk)

### Bookshine/Bookstart

Bookshine packs are available for deaf children as well as two standard Bookstart packs. The Bookshine booklist introduces ideas for books for children up to the age of five, based on ideas from parent carers, teachers, children and experts.

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

### The Cinema Exhibitors' Association (CEA)

The CEA card lets someone accompanying a deaf person to a participating cinema get a free ticket. There is a small administrative fee for the card. Terms and conditions, an application form and a list of participating cinemas are on the website.

[www.ceacard.co.uk](http://www.ceacard.co.uk)

[info@ceacard.co.uk](mailto:info@ceacard.co.uk)

### Forest Bookshop

Supplies books and other resources on deafness and deaf issues.

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

## TV programmes

There are a number of programmes that are targeted at deaf people and which can be viewed online. Visit:

### See Hear TV programme (BBC 2)

[www.bbc.co.uk/programmes/b006m9cb](http://www.bbc.co.uk/programmes/b006m9cb)

### BSL Zone, Community Channel

[www.bslzone.co.uk/bsl-zone](http://www.bslzone.co.uk/bsl-zone)

## Useful organisations and websites

The following organisations and websites provide information, advice or support. Some of them may have information or services that will help you, whilst others may not be relevant for your family. They are listed in alphabetical order. There will be other services not listed here that can provide information and advice. Ask your health visitor, **Teacher of the Deaf**, GP or anyone else working with you about other organisations. You could also ask parent carers of other deaf children.

### Action on Hearing Loss (formerly RNID)

A charity working for a world where hearing loss does not limit or label people, where tinnitus is silenced and where people value and look after their hearing.

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

[informationline@rnid.org.uk](mailto:informationline@rnid.org.uk)

Information line (freephone): 0808 8080123

Text phone: 0808 8089000

### Association of Speech and Language Therapists in Independent Practice (ASLTIP)

This is a professional body for speech and language therapists working independently.

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

01494 488306 (answerphone)

### Auditory Verbal<sup>UK</sup>

A registered charity providing auditory verbal therapy (AVT) services, including intensive, family-based intervention that aims to enable babies, infants and children who are deaf to learn to listen and talk.

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

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

01869 321492

### British Deaf Association (BDA)

The BDA was founded in 1890 and works to make sure that the Deaf community and British Sign Language (BSL) are recognised in the UK.

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

[admin@bda.org.uk](mailto:admin@bda.org.uk)

### British Deaf History Society

The society has a website where you can find out about events and buy books about deaf history. It also has a research library where people can research deaf history.

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

### Burwood Centre

This is an independent assessment centre for any child with a hearing impairment, irrespective of their communication mode or any other difficulties they may have (such as specific or general learning difficulties, physical difficulties, etc.).

[www.maryhare.org.uk/about-burwood](http://www.maryhare.org.uk/about-burwood)

[f.mcmenemy@burwoodcentre.org.uk](mailto:f.mcmenemy@burwoodcentre.org.uk)

### The Buzz

A website for deaf children and young people, where they can find out information, share their experiences and have fun.

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

### CHARGE Syndrome Family Group

This group for people with CHARGE syndrome and their families is a positive network of individuals, parent carers, families and practitioners who share ideas, experiences, information and give vital support.

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

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

020 82653604

### Cochlear Implanted Children's Support Group (CICS)

This group provides contact, information and support at any time before, during or after a child's cochlear implant operation.

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

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

020 88768605

### The Communication Trust

A coalition of nearly 50 voluntary and community organisations with expertise in speech, language and communication. It harnesses its collective expertise to support the children's workforce to support the communication needs of all children and young people, particularly those with speech and language communication needs (SLCN).

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

020 78432526

### Contact a Family

A national charity providing support and advice to parent carers of children with additional needs.

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

0808 8083555

### Council for Disabled Children (CDC)

The CDC is the umbrella body for the disabled children's sector in England, with links to other UK nations.

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

### Cued Speech Association UK

A national charity that provides information, advice, courses and learning materials on cued speech.

[www.cuedspeech.co.uk](http://www.cuedspeech.co.uk)

[info@cuedspeech.co.uk](mailto:info@cuedspeech.co.uk)

01803 832784

Text phone: 01803 832784

### DeafBooks.co.uk

DeafBooks.co.uk publishes British Sign Language (BSL) books, guides, dictionaries, posters, flashcards, downloads and mobile applications, available from Amazon.

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

[cath@deafsign.com](mailto:cath@deafsign.com)

01642 580505

### Deafinitely Theatre

A deaf-led theatre company based in London, which puts on plays, runs courses and workshops, and has mentoring opportunities for deaf young people interested in theatre.

[www.deafinitelytheatre.co.uk](http://www.deafinitelytheatre.co.uk)

### Deaf Education through Listening and Talking (DELTA)

A nationwide support group of teachers and parent carers of deaf children. It provides support, information and advice to guide parent carers in helping their children develop speech and to live independently within a hearing society.

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

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

0845 1081437

### Deaf Ex-Mainstreamer's Group (DEX)

DEX is a deaf-led organisation that focuses on the experience of deaf children in mainstream education.

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

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

### Deaf Parents Deaf Children (DPDC)

DPDC is a group for deaf parents with deaf children from all over the UK.

[www.deafparentsdeafchildren.co.uk](http://www.deafparentsdeafchildren.co.uk)

[hello@deafparentsdeafchildren.co.uk](mailto:hello@deafparentsdeafchildren.co.uk)

### Deaf Parenting UK

A charity that provides specialised support for deaf parent carers, focusing on enabling, empowering and supporting deaf parent carers and deaf parent carers-to-be.

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

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

SMS: 07928 842529

### Deafness Research UK

The UK's only national medical research charity for hearing-impaired people.

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

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

020 71642290

Text phone: 020 79151412

### DVD subtitles

This website helps you find DVDs of TV and film with English subtitles. It includes a top 50 list of subtitled DVDs, current bargains and has a section where you can complain if you are frustrated with the lack of choice of films with subtitles.

[www.dvd-subtitles.com](http://www.dvd-subtitles.com)

[fb@dvd-subtitles.com](https://www.facebook.com/dvd-subtitles.com)#

### The Ear Foundation

Supports children and young people with cochlear implants, their families and practitioners.

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

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

0115 9421985 (voice and text)

### 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.

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

0114 2700214

### Equality and Human Rights Commission

An independent body set up to secure civil rights for disabled people.

Helpline England: 0845 6046610

Minicom: 0845 6046620

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

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

### Family Action (formerly Family Welfare Association)

Provides a wide range of support to children and families living with poverty, ill health and social isolation.

[www.family-action.org.uk](http://www.family-action.org.uk)

020 72546251

### Family Fund

Provides grants and information to families caring for a severely disabled child under 16.

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

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

08449 744099

Minicom: 01904 658085

### Family Sign Language

A free, practical and interactive website to help families with deaf children up to the age of five learn basic British Sign Language (BSL) together.

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

### Genetic Alliance UK (formerly Genetic Interest Group)

A national alliance of organisations that supports children, families and individuals affected by genetic disorders.

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

[mail@geneticallianceuk.org.uk](mailto:mail@geneticallianceuk.org.uk)

020 77043141

### hiype

Advice, support and information for deaf young people who are working or studying.

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

### I CAN

This is the children's communication charity. It aims to ensure that no child who struggles to communicate is left out or left behind.

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

Switchboard: 0845 2254071 or 020 78432510

Information: 0845 2254073 or 020 78432552

### 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 0184016

### Include Me Too

Supports disabled children and young people, and their families, from black, ethnic minority and other marginalised backgrounds, and aims to promote and support all disabled children and young people's rights.

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

01902 3999888

### Kidscape

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

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

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

Helpline for parent carers: 08451 205204

020 77303300

### The Makaton Charity

Makaton is a recognised approach to teaching communication skills for people with communication and learning difficulties of all ages.

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

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

01276 606760

### Medikidz

Learn about conditions, treatments and medicines in the MediPedia section (currently still under construction). Deaf children and young people can get the facts on medical issues that affect them or their friends, watch fascinating videos and follow links to recommended websites and associations.

[www.medikidz.com/home](http://www.medikidz.com/home)

[info@medikidz.com](mailto:info@medikidz.com)

### Meningitis Trust

Offers a range of information, free professional services and community-based support for people affected by meningitis.

[www.meningitis-trust.org](http://www.meningitis-trust.org)

[info@meningitis-trust.org](mailto:info@meningitis-trust.org)

Freephone helpline: 0808 8010388

01453 768000

### National Cochlear Implant Users Association (NCIUA)

The NCIUA provides a forum for users of cochlear implants, their partners and families.

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

[enquiries@nciua.co.uk](mailto:enquiries@nciua.co.uk)

01494 723962

### The National Deaf Children's Society (NDCS)

NDCS supports families of deaf children. It provides clear and balanced information on all aspects of childhood deafness, including temporary conditions such as glue ear.

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

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

Freephone helpline: 0808 8008880

Minicom: 020 7490 8656

### Parent Partnership Services (PPS)

PPS offer advice and support to parent carers of children and young people with special educational needs. They are free, impartial and confidential services available in every local authority.

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

### Railcards

Find out more about a disabled person's railcard and how to apply. If your deaf child qualifies for a card, they could save a third of the price on most rail fares in Britain. A person travelling with your child as a carer can also claim the same discount.

[www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk)

[disability@atoc.org](mailto:disability@atoc.org)

### Royal College of Speech and Language Therapists (RCSLT)

A professional body of and for speech and language therapists in the UK and Ireland that sets professional standards.

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

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

020 73781200

### SENSE

A national charity that supports and campaigns for children and adults who are deaf-blind.

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

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

0845 1270066

Text phone: 0845 1270062

### Short Breaks Network

Its vision is of a society where disabled children and young people and their families can enjoy full social inclusion.

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

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

0117 9415361

Text phone: 0117 9415364

### Sibs

The UK charity for people who grow up with a disabled brother or sister. Resources and information are available for parent carers and siblings.

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

### The SignAlong Group

A charity that helps children and adults with impaired communication to understand and express their needs, choices and desires using sign language.

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

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

0845 4508422

### Signature

Promotes communication between deaf and hearing people by offering high-quality, nationally recognised assessments and accreditation in sign language and other forms of communication used by deaf people.

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

[durham@signature.org.uk](mailto:durham@signature.org.uk)

0191 3831155

Text: 0191 3837915

### Text Relay (formerly Typetalk)

This is the national telephone relay service that enables deaf, deaf-blind, deafened, hard of hearing and speech-impaired people to communicate with hearing people anywhere in the world.

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

[helpline@textrelay.org](mailto:helpline@textrelay.org)

### Signed Performances in Theatre (SPIT)

SPIT promotes British Sign Language-interpreted theatre performances. You can search for performances on its website.

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

### Signed Stories

An ITV website designed primarily for deaf children, although hearing children will enjoy it too. It is a fun, busy website with subtitles and sign language, which encourages children to explore and offers easy access to a wide range of British books.

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

### Sounding Board

This chat forum, set up by the Ear Foundation, has a section for deaf teenagers who have a cochlear implant/s or are thinking about getting one. Young people can get advice from other teenagers who have a cochlear implant/s, read about their experiences, ask about using an implant with an iPod, phone, radio aid and other equipment, and get useful tips.

[soundingboard.earfoundation.org.uk/teens](http://soundingboard.earfoundation.org.uk/teens)

### Stagetext

Provides information on theatre performances that have captions – speech is converted into visible text on stage.

[www.stagetext.org#](http://www.stagetext.org#)

[enquiries@stagetext.org](mailto:enquiries@stagetext.org)

### Treacher Collins Family Support Group

This group provides support, information and advice to families with Treacher Collins syndrome and first and second arch syndrome, atresia of the ear and any other condition combining conductive deafness with facial/head malformations.

[www.treachercollins.net](http://www.treachercollins.net)

[mail@treachercollins.net](mailto:mail@treachercollins.net)

01603 433736

Text phone: 01603 433736

### UCL Ear Institute and Action on Hearing Loss Libraries

A cooperative venture between Action on Hearing Loss and University College London, these libraries cover all aspects of hearing, speech and language, and specialise in literature on deafness, from academic journals to children's books.

[www.ucl.ac.uk/library/rnidlib.shtml](http://www.ucl.ac.uk/library/rnidlib.shtml)

[rnidlib@ucl.ac.uk](mailto:rnidlib@ucl.ac.uk)

Ear Institute/Action on Hearing Loss (and text phone): 020 34565145

RNTNE Hospital: 020 79151300

### UK Deaf Sport

A charity that encourages deaf young people to try sport and enjoy it!

[www.ukdeafsport.org.uk#](http://www.ukdeafsport.org.uk#)

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### Usher Syndrome

A website about Usher syndrome, which is the most common condition that affects both hearing and vision. The major symptoms of Usher syndrome are hearing loss and an eye disorder called retinitis pigmentosa, or RP. Retinitis pigmentosa causes night-blindness and a loss of peripheral vision (side vision) through the progressive degeneration of the retina.

[www.usherlife.co.uk/index.html](http://www.usherlife.co.uk/index.html)

### Your Local Cinema

This website tells you which of the latest films are now showing with **subtitles** and where they are on in the UK. You can search by your town.

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

## Glossary

**Acquired deafness** – Hearing loss that was not present at birth but developed later, either during childhood or adulthood.

**Additional need** – A condition, difficulty, challenge or special educational need, whether diagnosed or not, that means a child is likely to need additional support that is not normally provided by universal services.

**Asymmetrical deafness** – Deafness that is different in each ear.

**Audiogram** - A chart on which some of your child's hearing test results will be written. It shows you how loud a sound has to be, and at what frequency, before your child can hear it. Sometimes separate charts will be used to show results for each ear.

**Audiologist** – A practitioner who carries out hearing tests, interprets the results to determine the level of deafness and can advise on the options available. They also make earmoulds, fit hearing aids and review progress.

**Audiology** – The medical term for the study and measurement of hearing and deafness.

**Benefits** – Money paid by the government to people in certain situations.

**Bilateral deafness** – Deafness in both ears.

**Cochlear implant** – A device to improve hearing for children, young people and adults who get insufficient benefit from conventional hearing aids. It comprises an internal receiver/electrode package, that is surgically implanted behind the ear and into the cochlea, and an external speech processor worn on the ear like a hearing aid.

**British Sign Language (BSL)** – A visual and spacial grammatical language used by deaf people in the Deaf community as their native or first language, and recognised by the UK government as a full, independent national language. It has the same range of meaning as spoken languages.

**Communication** – Using language (including speech, sign language, body language, etc.) to get meaning across and to understand what other people mean.

**Communication support worker (CSW)** – A practitioner who works in different situations, including schools, colleges and universities, to help deaf people communicate with others.

**Conductive deafness** – When sound cannot pass efficiently through the outer ear and middle ear to the cochlea and auditory nerve.

**Diagnosis** – Identifying that a child is deaf.

**Educational psychologist** – A practitioner who helps children or young people who are having problems in an educational setting.

**Emotional vocabulary** – Ways to describe your feelings.

**Emotional well-being** – Feeling good about yourself, having positive relationships with others, having language and communication skills to communicate your feelings, and being able to bounce back from negative experiences.

**Fingerspelling** – Using the British Sign Language alphabet to spell out words.

**Glue ear** – A build-up of fluid in the middle ear, which makes it harder for the sound to travel from the outer ear to the inner ear. It can cause temporary deafness.

**Hearing aid** – A device to amplify sound. Air-conduction hearing aids do this by channelling the amplified sound through an earmould into the ear. Bone-conduction hearing aids convert the amplified sound into vibrations that are transferred across the skull bone to the cochlea.

**Hearing implant centres** – Specialist health/NHS services that assess, fit and provide long-term support for implantable hearing equipment, such as cochlear implants, middle ear implants and bone-anchored hearing aids.

**Late onset deafness** – Deafness that is not present at birth.

**Levels of deafness** – How much hearing loss someone has, described as a decibel (dB) hearing level, or as mild, moderate, severe or profound deafness.

**Lip-reading** – Understanding speech from the movements of someone's lips.

**Lipspeaker** – A practitioner who silently repeats someone else's speech using rhythm and phrasing in a clear way that a deaf person can understand.

**Local authority** – Local government (the council for the area), which runs services in the community, including education and provision for children with special needs.

**Mainstream school** – A primary or secondary school that is state funded.

**Mainstream school with resource provision** – A mainstream school with a specialist resource base providing specialist hearing-impaired provision or meeting a broad range of special needs.

**Mixed deafness** – Sensori-neural deafness as well as conductive deafness, such as glue ear.

**Practitioner** – Someone who is employed to work with children from whatever background.

**Progressive deafness** – Loss of hearing that gets more pronounced over time.

**Radio aid** – This consists of a transmitter and a receiver. The transmitter, used by the person who is talking (for example, a teacher or a lecturer), sends sounds by radio waves to a receiver, used by the deaf child/adult.

**Residual hearing** – Any hearing that a deaf person has.

**Sensori-neural (or nerve) deafness** – A permanent hearing loss due to a fault in the inner ear (usually because the hair cells in the cochlea are not working properly) or auditory (hearing) nerve.

**Sign language interpreter** – A practitioner who uses sign language to interpret spoken language to a deaf person.

**Special educational need** – A need or needs that require extra or specialised provision so a child can access their education.

**Special educational needs coordinator (SENCO)** – A teacher who identifies children with special educational needs at school and makes sure they receive appropriate support.

**Special school** – A school that caters for children with special educational needs.

**Speech and language therapist** – A person who offers assessment, treatment and advice to people of all ages who have communication difficulties.

**Speech to text reporter** – A person who types information on a screen or a laptop for deaf people in further and higher education and other formal settings.

**Statement of special educational needs** – A document written by the local education service that says what a child needs in order to learn and the support that the education service will give to help meet their needs.

**Subtitles** – Words that appear on the TV screen and show as closely as possible what the programme's characters or presenters, etc., are saying.

**Symmetrical deafness** – Deafness that is the same in both ears.

**Teacher of the Deaf** – A qualified teacher, who is also qualified to teach deaf children. They provide support to deaf children, their parents and family, and to other practitioners who are involved with a child's education.

**Unilateral deafness** – Deafness in one ear.

# Early Support

for children, young people and families

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

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

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