Information for families

Deaf children with additional needs
Our vision is of a world without barriers for every deaf child.
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Why we have produced this booklet

We have produced this booklet for parents and carers of deaf children with additional needs.

Having a deaf child with additional needs affects you, your partner and your family. Family, friends and neighbours may react to your child’s deafness in different ways. You may like to meet other families who also have a child with additional needs (for example, you can contact the NDCS events team about events run for families with children with additional needs).

No single booklet can give you all the answers, but this booklet aims to start answering some questions and suggest where to go for more information and support.

NDCS uses the word ‘deaf’ to refer to all levels of hearing loss.

Understanding additional needs

Any extra need can be worrying. If you understand the need you can act, find others who have had a similar experience, get advice, start to feel in control again, and enjoy being a family. Sometimes you may feel you know more than the professionals involved and this can be very frustrating. Parents and professionals both have lots to contribute to any discussion about needs, and how these may best be met for your child. And they both have lots to learn.

It is estimated that up to 40% of all deaf children have some extra health, social or educational need. These needs, known as additional needs, arise as a result of other conditions ranging from asthma, colour blindness and dyslexia to severe learning and physical disabilities. Also, every child has their own personality and learning style. They may be someone who watches or someone who joins in, someone who likes lots of activity or someone who is naturally quiet.

It is sometimes easy to let the challenges your child faces overwhelm other aspects of their personality. This is called ‘overshadowing’. Many parents say that when they are at an appointment, professionals focus on only one aspect of the child and ignore other aspects. For example, a child who has Down’s syndrome may be seen firstly as having a learning disability, secondly as having a hearing loss and thirdly as an outgoing friendly child, rather than being seen as a whole person.

All levels and types of deafness affect children differently. You may hear phrases such as ‘it’s the least of their problems’ or ‘given other challenges, we don’t need to worry about hearing’. It is inappropriate for any professional to decide whether a hearing loss is important to you or your child. If you are concerned about your child’s hearing, your concerns should be taken seriously.

This booklet was compiled by Wendy McCracken, Senior Lecturer in Education of the Deaf at the University of Manchester; and Pauline Walker, Deputy Director: Families.

We would like to thank all the parents who contributed to this booklet for their time and experience.

The parents’ views are their own and not necessarily endorsed by NDCS.
Finding out your child has additional needs

For some children it will be clear from birth, or within the first months, that there are special needs (for example, when a child has Down’s syndrome or because of the physical differences of babies who spend time in a neonatal intensive care unit). For others the deafness may be identified very early in life and then, as the child grows up, some aspects of their development may be slower than expected. For other children, difficulties and differences may be noticed by their parents or by the health visitor or the family doctor, as part of routine assessments. You, your health visitor or your family doctor may refer your child for more assessments. In some cases, extra needs may not be spotted until the child is a little older (for example, eyesight problems) or at school (for example, dyslexia or a specific language disorder). In some cases, illness (such as meningitis) or accidents may cause deafness and other difficulties.

When your child’s deafness is first identified you should be referred to a specialist teacher of the deaf who is a teacher who has taken further training to become qualified to teach deaf children. They provide support to deaf children, their parents and families, and to other professionals who are involved with a child’s education. For many families, the child’s teacher of the deaf may be the main person responsible for co-ordinating the support you and your child receive. They play an important role in helping parents to support their deaf child.

As part of the England government’s Early Support Programme, the professionals who work with you should give you a number of publications with information on your child’s condition, the sort of support services you can expect to meet, and to help you make informed choices for you and your child. There is also a ‘Family Pack’ of resources to both help you work in partnership with the professionals you will meet and materials to help you monitor your child’s progress and development.

One of the Early Support publications is the ‘monitoring protocol’. It is designed for children who are at the development stage of a child aged three or under. The monitoring protocol may help you and others to see how your child is progressing. By filling in the monitoring protocol you can check if any areas of development are delayed, and identify any areas that need support. If you would like them to, your teacher of deaf children can help you fill in the monitoring protocol. You can then discuss any areas of concern with your teacher of the deaf, health visitor, social worker or family doctor.

Professionals you may meet

It is likely that you will receive support from a range of professionals. Sometimes these professionals work as part of a specialist child-development team. You may be referred to the child-development team. A list of some of the professionals who may make up this team are at the beginning of the next section. This team is responsible for assessing a child’s needs, identifying any areas of concern and planning how these needs can best be met.

The team may suggest that:

• other professionals become involved
• specific routines are introduced
• special equipment is needed
• medical treatment is needed, or
• no other action needs to be taken at this point.
Assessments
Assessments should be carried out by a team of people.
Here are some of the people who might be involved in an assessment.

- **Parents and carers** – You know your child best and provide all support and daily care.

- **Health visitor** – Your health visitor may see your child at your home or the local clinic. They can help to assess your child’s development and work closely with your family doctor.

- **Family doctor (GP)** – Your GP can refer you to appropriate services and support.

- **Teacher of the deaf** – Your child’s teacher of the deaf can provide support and assess your child’s communication skills.

- **Audiologist** – The audiologist is responsible for assessing your child’s hearing, and for fitting hearing aids and making sure they work well.

- **Consultant community paediatrician** – This is a doctor specialising in children’s health. They may discuss any necessary assessments and plan these with you.

- **ENT consultant** – This is a doctor who specialises in the ear, nose and throat. They have overall responsibility for the medical care of your child in these areas.

- **Speech and language therapist (SLT)** – These help children with communication skills – developing speech or other communication systems. They can help with a wide range of difficulties and disabilities (for example, problems with swallowing).

- **Key worker** – This is a lead person responsible for co-ordinating services and appointments. They can be a service provider or an independent key worker.

- **Educational psychologist** – An educational psychologist can support and give advice on statements of special educational needs (SEN), and help schools to develop ways of working with children.

- **Social worker** – A social worker can provide practical help and advice about counselling, transport, home help, obtaining equipment and other services.

- **Optometrist** – Optometrists assess eyesight and can prescribe glasses.

- **Ophthalmologist** – This is a doctor who specialises in assessing the eye, and in diagnosing and treating disorders of the eye.

- **Geneticist** – This is a doctor who specialises in investigating the genetic cause of a disability.

- **Occupational therapist** – An occupational therapist works with children who have co-ordination problems or physical disabilities. They assess children, and plan and give advice on individual programmes of care. They may also refer children to other services.

- **Physiotherapist** – These assess children and give advice on physical disabilities and possible treatments.

A range of other professionals may also be involved.
Assessments are just like a jigsaw puzzle where lots of pieces of information are joined together to see the full picture. When children are deaf and have additional needs, collecting all the pieces of the jigsaw can be even harder. Sometimes even sophisticated tests only tell us part of the answer. Professionals may find it hard to admit that some children’s needs are so complex that they feel their professional skills and knowledge are not enough.

By working and learning together, families, children and professionals can find a positive way forward. Assessment on its own is meaningless unless it leads to action that improves the experience of your child.

Typical questions you may like to ask professionals include the following.

- What assessments are planned?
- Why is the assessment being done?
- What will the results of the assessment tell us?
- Where can I get more support?
- What services should I receive and what else is out there that might be useful or of interest?

Every child is different and will have different needs. Parents play an important role in any assessment. They understand many things about their child that can be useful for professionals to take account of.

The following statements from parents, and the professional’s response, show how parents’ comments have helped during an assessment.

**Sam always bangs with his hands when he wants a drink or snack.**

**Professional’s response:**

“Sam can communicate his needs so a simple picture system could help him learn to make choices. A digital camera would be very useful to help make a picture diary of things that are important to Sam.”

**Aneela won’t let me brush her hair or teeth without a fight, and washing her face is always a struggle.**

**Professional’s response:**

“It is likely to be very hard to fit hearing aids, so a simple ‘desensitisation programme’ should be used. This would help relax Aneela too.”

**Helen screams when the phone rings. She gets really upset and bad tempered.**

**Professional’s response:**

“Helen may be very sensitive to loud noises and needs this to be taken into account if she has hearing aids.”

**I know you think she’s deaf but she’s not. I can show you. Look, every time you make a noise, she moves her little finger. Every single time.**

**Professional’s response:**

“Carly was thought to have so many disabilities she would be unable to complete a basic hearing test. This turned out to be quite wrong.”

**Cal seems to bump into everything. I don’t know if it’s because he’s growing so quickly.**

**Professional’s response:**

“Cal may have balance problems associated with hearing loss, may need his vision checked, or may just be growing quickly.”
Where assessments might be carried out

Your child may be assessed at:

• your home
• a local clinic
• a childcare centre
• an early years centre
• a local hospital
• a regional hospital
• school
• college.

You should be asked to give permission before your child is assessed, particularly if you are not going to be present (for example, if the assessment is carried out in school). You have a right to be given details of any assessment procedure, together with a copy of, and clear explanation of, the results. If your child has very complex needs, you may be referred to a specialist assessment centre where professionals have more experience in meeting those needs or where there is specialist equipment.

If you’re asked to go to any appointment, here are some questions you could ask.

• What is the appointment for?
• How long will the appointment take? (So you can plan for food, drinks, childcare and so on.)
• What will happen at the appointment?
• Do I need to prepare my child for the appointment? (For example, make sure they are sleepy or wide awake, explain the tests to them and so on.)
• Can I take a family member or friend with me?
• Can an appointment be arranged to fit in with other family demands or travel difficulties?

Getting a diagnosis

Some deaf children with additional needs have a condition that has been identified (for example, Down’s syndrome or cerebral palsy). Sometimes it is impossible to diagnose (identify) a particular condition and a more general term may be used (such as ‘global developmental delay’ or ‘learning disability’). In both cases the child has been given a ‘label’. This means that a specific need or condition has been identified. You should receive advice or information to help you understand your child’s needs.

The label may also do the following.

• Provide access to services like respite care, physiotherapy, speech and language therapy, or to funding for specialist equipment
• Help families and service providers to adapt and be more aware of meeting a child's needs and supporting their development
• Provide access to medical services (for example, for diabetes, coeliac disease, short-sightedness)

It is very important that labels attached to children do not act as a barrier to them getting the necessary support. So a deaf child with Down’s syndrome has just as much right to a teacher of the deaf and good audiological care as any other deaf child. Your expectations should be high, and shared with your support services so that you can jointly work towards them.

It can be much harder for a professional to assess a child who is deaf and has other disabilities. For example, the deafness may make it hard to identify a language disorder or to assess eyesight because of the need to hear instructions and to work in the dark during an assessment. Or, a delay in speaking or signing may be due to deafness, a general delay in development or a physical disability.
Assessing a child’s deafness can be hard if the child has several extra needs. The test equipment uses information collected from children at the stage of development that is usual for their age. So the results may be misleading for certain disabilities. For example, a commonly used test called ‘auditory brainstem response’ (ABR), carried out when a child is asleep or sedated, may show no response for a child with hydrocephalus (fluid around the brain). This does not mean the child has a hearing loss, it means we do not know if the child has a hearing loss. Other types of hearing test will also need to be carried out to get the full picture.

Checking eyesight

Most of the information children use to learn about the world comes from what they see and hear around them. For a deaf child, what they see plays an important role in helping them to gain language skills and explore their world. This means that regularly checking your child’s eyesight is important.

Knowing about your child’s eyesight tells you the following.

- What skills are already developed or need to be developed (for example, following moving objects)
- What level of light the child works best in
- Whether shiny surfaces help or cause problems
- Whether a particular colour is helpful or unhelpful
- Whether the child needs glasses, contact lenses or protection from strong light
- Whether your child should be approached from a particular side
- Whether an eyesight problem will affect your child’s ability to lipread, see signs, and learn to read
- What adaptations will be helpful (for example, does patterned wallpaper make it harder for your child to pick things out than a single block of colour would?)

If your child does have severe eyesight problems, they should be referred to a specialist teacher who will provide support and suggest any specialist equipment or adaptations you may need. There is a range of terms associated with eyesight problems. This can be confusing.

For more information, contact us for our publication *Vision care for your deaf child*. For children with several needs, the organisation SENSE offers a free assessment and advisory service visit [www.sense.org.uk](http://www.sense.org.uk).

Medical conditions

- **Attention deficit hyperactivity disorder (ADHD)**
  This typically includes lack of concentration, acting on impulse, and hyperactivity. The child will have particular problems with organising and planning. It can be difficult to get ADHD diagnosed in deaf children as behaviour associated with deafness may complicate the diagnosis. It is important to have a specific diagnosis of deafness and ADHD, as this is important for taking the right action. The assessment should be made by a team made up of different professionals. Managing ADHD may involve additional educational support, counselling, medication or removing certain things from the child’s diet.

- **Autistic spectrum disorder**
  This term describes a range of disorders associated with poor understanding of social situations, poor communication skills, repetitive actions and resistance to changes in routines. The range of disorders includes Asperger’s syndrome, pervasive developmental disorder (PDD) and Rett’s syndrome. Identifying an autistic spectrum disorder is complex. An assessment is based on observations and practical tests rather than medical investigations. Managing PDD may involve a mixture of behaviour management, education, speech and language therapy, drug therapy and family support. Every child is different and their needs have to be carefully considered. Some children with PDD can use hearing aids if they are introduced in a controlled
environment where there isn’t a lot of other noise but there are interesting and relevant sounds to hear. Children may take some time to adjust to the new sounds and to make sense of them. However, hearing aids can cause problems for some children with PDD, who find the extra sounds overwhelming and confusing. In this case it would be very important to balance any real gains against the disruption caused. For some children with PDD, this disruption may reduce as the child gets older. For a deaf child who cannot cope with hearing aids, a soundfield system in school may be useful.

For more information about soundfield systems see our booklet *Radio aids – an introductory guide.*

**Cerebral palsy**
This condition varies a great deal in the way it affects children. The assessment of a child’s ability to learn may be complicated by a child not being able to respond physically or through speech. Cerebral palsy may also make it more difficult to carry out and interpret hearing tests. It is very important to share information about your child’s hearing and listening behaviour with your child’s teacher of the deaf and audiologist. This helps to build a picture of your child’s hearing. Children may use a range of specialist equipment. It is very important that you tell the audiologist if your child is using a ‘side lyer’ or wheelchair with a head guard as they need to take this into account when fitting hearing aids. It is very important that any child with cerebral palsy has a communication method that is easy to use, easily accessible and allows for development (see Communication section).

For more help and resources visit [www.scope.org.uk](http://www.scope.org.uk) or phone the cerebral palsy helpline on 0808 800 3333.

**Down’s syndrome**
Down’s syndrome is commonly associated with a learning disability, although the degree of this varies. Children with Down’s syndrome often have a hearing loss caused by a build-up of fluid in their middle ear. Like other children with additional needs, special care should be taken when analysing the results of hearing tests. Children with Down’s syndrome may also get sensori-neural (nerve) deafness around puberty. So it is important that hearing levels are checked regularly.

As children with Down’s syndrome have very small ear canals, this must be taken into account when hearing aids are fitted. Real ear measurements (measurements of the actual level of sound from the hearing aid recorded in the ear canal) should be used to make sure the hearing aid is set correctly and is not too loud. Many children with Down’s syndrome go to local mainstream schools. They should have the support of a classroom assistant, a teacher of the deaf and a speech and language therapist.

For more information, contact Down’s Syndrome Association as follows.
Website: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)
Phone: 0845 230 0372
Fax: 0845 230 0373

For more information and further resources, see our booklet *Down’s syndrome and childhood deafness* which you can order from the NDCS helpline.

**Dysarthria**
This is where there is a problem with the muscles that control speech. This is commonly associated with a general condition like cerebral palsy.

**Dyslexia**
This is a specific reading disability. A child may find it difficult to understand that words are made of different sounds. A child may also have memory problems that make it hard for them to remember the structure of a sentence long enough for them to understand what it means. Children may find it difficult to solve problems and have a tendency to act on impulse.
• **Learning disability**

Learning disabilities vary from mild to very severe. They frequently occur with a range of other disabilities. Standard hearing tests are based on children at the usual stage of development for their age. Specialist expertise is needed to identify specific needs and appropriate support, and to monitor progress. A wide range of professionals is likely to be involved. This may cause difficulties for families and carers. It is important that any child with severe learning disabilities is seen as a whole child rather than a number of difficulties. All children have their own preferences, personalities and behaviour. Communication may be very challenging, but it is essential families are given appropriate support from speech and language therapists and teachers of the deaf to make sure communication is developed.

For more information, contact MENCAP.
Website: [www.mencap.org.uk](http://www.mencap.org.uk)
Email: help@mencap.org.uk
Phone: 0808 808 1111
Textphone: 07717 989 029

• **Specific speech and language disorders**

When children who can hear have a level of language that is well below their general ability they can be classified as having a ‘specific language disorder’. Language development may also be expected to be delayed if deafness is not diagnosed and managed early on. A language disorder may be thought to be present when a child has specific problems understanding spoken or sign language, or a specific problem using speech or sign, above what may be expected for the level and type of hearing loss. A disorder is difficult to identify without the input of an experienced speech and language therapist who specialises in deafness.

**Communication**

Lack of communication is a major challenge. Everyone communicates. It may not always be easy to see, understand or respond to quickly, but it is there. The form it takes may vary.

The most important starting point in communicating is to list what your child can do, what they like and don’t like, and how you know this. It is very easy to make a long list of things a person can’t do – can’t play the piano, speak Spanish, fill in their tax returns, eat clams or ride a unicycle. This does not mean you know the person. It is looking at what a person can do that we identify a starting point to work from.

Can you think of four things your child loves and four things they do not like? You know this because your child is communicating. So your child does communicate. Sometimes the starting points for developing communication skills may be hard to find, but they are there.

Sometimes the challenge might come later when lots of skills are developed and then something prevents further progress. A diagnosis or label might be given early on that makes you worry about the future. This label may later be dismissed as not being relevant any more. The whole situation can be confusing and alarming.

If a child cannot influence the world around them or make things happen, this can sometimes result in them turning to themselves for stimulation (for example, by rocking or by hitting or biting themselves). It is important for children at the earliest stages of communication to experience cause and effect and to make choices. Your child’s teacher of the deaf or speech and language therapist should be able to give you advice and ideas to try.

The ACE Centre Advisory Trust has a national network that supports children and families using or wanting to find out about alternative methods of communication for those with severe disabilities. The centres help people with complex physical and communication difficulties to get access to information on communication technology and a range of communication methods and equipment. Contact details can be found in *Useful Organisations* on page 23.
Communication may be through any one, or a mixture, of the following.

- **Speech**
  This may be English, Urdu, Farsi, Syhletti, French, Swahili or any other spoken language.

- **Cued speech**
  This is a system where sounds which look the same on the lips (and so are hard to understand) are communicated by using specific handshapes near the mouth.

  For more information, visit www.cuedspeech.com

- **Sign language**
  British Sign Language is a unique language unrelated to spoken English.

  For more information see the Family Sign Language Curriculum section of our website at www.ndcs.org.uk and also the Family Sign Language website at www.familysignlanguage.org.uk

- **Signed system**
  There is a range of signing systems that have been developed to help improve communication with people who have disabilities. These are based on the structure of spoken English and may borrow some BSL signs (for example, MAKATON) or have their own sign system (for example, PAGET/GORMAN).

- **Symbols**
  A number of symbol systems have been developed (for example, BLISS). There are also a number of very useful electronic resources that incorporate symbol systems and BSL (for example, Widgit).

  For more information about Widgit, visit the website at www.widgit.com

- **Objects**
  It isn’t always possible to have the real thing close to hand, so objects can be used to stand for something else (for example, a spoon might mean dinnertime, a key on a chain might mean going in the car, a sponge might mean bath time).

It is important that your child knows what’s happening or is about to happen. You can use objects, symbols and pictures with signs or speech to help involve your child in what is going on. By setting a clear pattern of what is going to happen each day, your child will have the chance to develop an understanding of a pattern rather than things simply happening to him or her.

The system you use does not matter, as long as it’s effective and used by your child and all those in regular contact with him or her. Using one system such as speech should not rule out using another such as sign, pictures or objects. Most parents will use speech and support this by using any cues that help. A child may choose an object to let you know they are hungry or want to play, may sign an important word and use pictures to support their meaning or use their voice with symbols.

The really important thing is to have a system of communication that you and all the other people who are with your child regularly, agree with, use and understand.

The important points are that any system you use should:
- be used at home and school;
- be easy to use;
- be used by all the family, carers, professionals and those in regular contact with your child; and
- allow your child to express themselves and join in with the family and with school activities.

For more information about communication see our booklet *Communicating with your Deaf Child* or contact our Freephone Helpline on **0808 800 8880** (voice and text) or by email at helpline@ndcs.org.uk
Hearing aids

Your child may be offered hearing aids. There is a lot more information about hearing aids in our booklet *Hearing aids – information for families*. Here are a few points to consider for children who have additional needs.

Hearing aids are only useful if:

- they make the right sounds louder but protect the ears from loud sounds that may be uncomfortable
- they work properly, have their batteries changed regularly and faults are identified
- they are worn regularly
- there is something interesting to listen to, and it’s not too noisy in the background.

Your child will probably go through a phase of removing their hearing aids. It can be very frustrating to keep replacing them, especially if your child does not want them put back in. For deaf children with additional needs this situation is more complex. It may be more difficult to assess their hearing, to fit hearing aids and to measure the benefit. So they may be removing their hearing aids because it is fun and they can do it, to attract attention, or because they are too quiet or too loud. This is where it is important for you to identify when your child is happy to wear aids, when they are not, what sounds they prefer, and any sounds your child makes (not just speech), and where sounds seem too loud or not loud enough. This all helps your child’s audiologists to make sure hearing aids are programmed to best meet your child’s needs.

If your child’s hearing aids constantly fall out, or if they use a ‘side lyer’ or wheelchair with head guards, it is important for their audiologist to know as the hearing aids can be adjusted to specific situations.

Parenting tips

Parenting a deaf child with additional needs is similar and different to parenting any other child. Where there are differences, there are usually challenges so support and advice from other parents is often invaluable. The following pages contain a range of useful advice and tips from parents of deaf children with additional or complex needs.

**Parent to parent**

“Be around when required. Don’t wrap them in cotton wool but at the same time guard them against danger.”

*Colin and Marion, parents of Helen (age 5) – Learning difficulties and poor concentration*

“I mention her needs in a round about way, dropping it into conversation as if it was the most natural, normal thing without putting any emphasis on it at all!”

*Lesley, mother of Natalie (age 17) – CHARGE syndrome, partially sighted*

“With adults out in public I feel I am always having to apologise for him. I want to say, ‘He’s deaf with additional learning difficulties and global development delay,’ but by then he’s gone off to annoy someone else or get into some other kind of dangerous situation.”

*Jeanette, mother of Aidan (age 7) – Severe learning difficulties and global development delay*

“Meeting other parents is essential to parents’ emotional well-being. Despite being very busy I always give priority to events where I meet other parents.”

*Marie, mother of Alister (age 11) – Chromosome 18 q depletion – Main problems are moderate hearing impairment and autism*

“Even if children have different disabilities the impact is the same. I used to be quite shy with strangers but Grace’s disability has brought me out of my shell. I’m not scared now to say how I feel which is important and healthy for all parents with children with disabilities.”

*Dina, mother of Grace (age 3) – HDR or Barakat syndrome*
Communication

Communication is an important aspect of family life. In some cases it may be hard to identify how a child is communicating. Parents are best at understanding their own child.

A child may communicate by facial expression, using objects or pictures, symbols, signs, gesture or speech.

The successful development of communication skills supports all other aspects of parenting a deaf child with additional or complex needs. No single method of communicating is better than any other – the important thing is that it works for you and your child.

“Although Peadar is deaf I tend to talk to him loudly using basic words in a one-to-one scenario. I also find hand gestures useful for communicating, for example, holding my hands out to him for him to sit up or show him a face cloth when I am going to wash his face so he knows what is happening.

Because Peadar is deaf and has sight impairment he seems to respond very well to smells. Even though he is on a special diet and eats at different times to us, but he seems aware of when we are eating through what he can smell. He opens his mouth as if he is waiting for food and communicates with us in this way.”

Bernadette, mother of Peadar (10) – Downs syndrome, epilepsy, sight impaired, severe learning disabilities, doesn’t walk

“Communication is simple. By talking to him and showing him different things he knows what we are talking about. For example, if we show him a ball he knows it is time to play, and if we show him a cup he knows it is time to eat or drink. We have been working together with Jonathon for so long now that we know what he is trying to communicate, so it gets easier.”

Samuel and Linda, parents of Jonathon (11) – Epilepsy and low muscle tone, cannot walk or talk

“In order to communicate with Jonathon initially we needed to use very basic signs, for things like car and drink. We couldn’t live without them! Pictures are brilliant for telling them where they are going and what they will be doing, although it may be different for different children.”

John and Teresa, parents of Jonathon (9) – Down’s syndrome

“After a lot of rushing around the other day I said, ‘You have been brilliant today,’ – she beamed.”

Teresa, mother of Juliet (age 9) – Leopard syndrome including heart disease
“Ben is very positive about his processor. We have also talked about it as being Ben’s special processor. Always making him feel good that he has a processor and we don’t, so that he feels that he has something special.”

*Sally, mother of Ben (age 6) – Asperger’s syndrome*

“I use lots of facial expressions to show my praise along with thumbs up (‘Good stopping’ etc.) I always tell him what he has been good at.”

*Sally, mother of Ben (age 6) – Asperger’s syndrome*

“Learn basic signs and sign to the child from the earliest possible stage. Continue and reward for any form of understanding.”

*Michael, father of Callum (age 5) – Athetoid Cerebral palsy and renal failure*

“George’s favourite activities are singing games with actions. Because of his signing he is very in tune with hand movements and watches intently. He loves *Heads, Shoulders, Knees and Toes*. At first we found this hard to do because he will find it difficult to say ‘shoulders’ and it is more difficult for George to point to his shoulders so we changed it to ‘heads, tummies, knees and toes. Don’t underestimate the power of repetition. Recently on holiday my friend’s children attempted to teach George his favourite song, and solely through repetition, he had learnt it after two weeks. It takes him longer to pick it up, but he can do it now. Other children are a great help because they do not tire of something the way adults might!”

“Use realistic coloured toys. For example, do not present your child with a blue sheep – it is too difficult to explain and hard for them to understand the difference when they are presented with the real thing.”

“In the speech therapy classes designed for children with a developmental delay I was expected to sit behind my child, but doing this meant I missed him signing to me. Children with additional needs have a time lag. If I waved to George, he may not wave back for ten minutes. At first I would miss him waving and thought he could not do it. It is hard, but you need to learn to work at their pace, not yours.”

*Carole who is the mother of George, aged 20 months, shared a lot of tips about communication with us. George has Down’s syndrome and low muscle tone.*
**Choices for your child**

Can your child choose which drink, which food, which toy and so on? Parents at one of our weekend events for families with a child with additional needs were asked for practical suggestions.

“Taking digital photographs of familiar things drinks, food, toys, people – sticking it to card and laminating it or using plastic pockets.”

“Using objects, having each ready in a partitioned box to use round the house.”

“I got a shoe keeper that has plastic pockets and you can hang up. I put objects in it and hang it where she can reach. She can point to what she wants to do.”

“We use a symbol system that the school uses. We’ve labelled things round the house and in the car, and even in the garden.”

**Safety**

This is a challenging area. For some children road safety will be a very real issue, for others it may be eating something dangerous or choking on a meal. Every parent knows the value of teaching their child to be aware of danger, and parents of deaf children with additional or complex needs have said that this is an area where there are likely to be problems. Parents have developed strategies and found a range of useful and practical resources.

“Jonathan has no sense of danger. He doesn’t understand danger.”

*Samuel and Linda, parents of Jonathan (11) – Epilepsy and low muscle tone, cannot walk or talk*

“For safety in public you have to be constantly aware of where they are and what dangers are around. If necessary hold on to them. Jonathan wouldn’t stop to think if something were dangerous. You have to go over it again and again.”

*John and Teresa, parents of Jonathan (9) – Down’s syndrome*

“We need to take a lot of precautions with Peadar because he is epileptic. It is vital to keep him in a safe environment and to have an adult with him at all times. We have carpet in all the rooms in case he has a fit and the corners of the fireplace are padded to prevent him from hurting himself. When buying new tables and chairs we have to be careful that the legs are rounded so that he does not hurt himself. It is impossible to guard them against everything!”

*Bernadette, mother of Peadar (10) – Down’s syndrome, epilepsy, sight impaired, severe learning disabilities, doesn’t walk*

“Have lots of locks put on your house, especially window locks. The need for these have eased now Ben is 6 but it has only been in the last year that we can relax a little.”

*Sally, mother of Ben (age 6) – Asperger’s syndrome*
“Use toddler harness/reins when out, put locks on windows, make sure that the garden is secure and the gate is difficult to open. Use the child lock on the rear car door and employ general accident prevention as per any young child.”

Colin and Marion, parents of Helen (age 5) – Learning difficulties and poor concentration

“We find portable CCTV is great as it enables us to have a camera in Carmel’s room while she is sleeping and we can keep the monitor wherever we are in the house. It saves us running up and down the stairs if we need to check on her. We can remain constantly aware that she is OK, and she can still have her own space.”

Eileen and John, parents of Carmel (age 17) – Photosensitive epilepsy, anterior ectopic rectum, cerebral palsy, orthopaedic abnormalities, thyreotoxicosis, horseshoe kidney with some loss of function

“I use a harness when Grace has refused to hold my hand. As soon as I put it on she’s as good as gold and cooperates wonderfully.”

Dina, mother of Grace (age 3) – HDR or Barakat syndrome

“Other parents before you will have had the same problem and there are often suppliers of safety products to be found on the internet, e.g. car restraints which children can’t release, bicycles with supportive seats, identity bracelets, etc.”

Marie, mother of Alister (age 11) – Chromosome 18 q depletion – Main problems are moderate hearing impairment and autism

“Always tag your child when out with a wrist band with vital contact details – my child being deaf and autistic could not offer any information. He would not have been distressed when separated from us so it would have been hard for people to know he was lost. We lost him on two occasions on holiday. It was very frightening.”

Sally, mother of Ben (age 6) – Asperger’s syndrome

Your child’s emotions

It is important that your child can communicate their emotions to you. Barriers to communication often prevent this taking place effectively. Parents of deaf children with additional or complex needs stress the importance of finding some way in which to discuss emotions, even at young ages. In this section our parents suggest a variety of strategies, including: connecting with emotions through stories and books; using facial expressions and gestures; and making sure you include emotional vocabulary when developing communication.

“Ben used to get upset about crying, he didn’t like his tears. I always explained to him what he was feeling: “Ben’s sad”, so he could understand what he was feeling.”

Sally, mother of Ben (age 6) – Asperger’s syndrome

“When George is tired he takes his hearing aids out and puts them beside him as if to say, ‘That’s enough for today’.”

Carole, mother of George (20 months) – Down’s syndrome and low muscle tone

“We know the difference between his cries. He has a different cry when he has hurt himself compared to when someone has taken his toy. We can tell he is hungry by his cry.”

Samuel and Linda, parents of Jonathon (11) – Epilepsy and low muscle tone, cannot walk or talk

“Dealing with emotions can be very frustrating. Jonathon couldn’t understand what he is feeling and we found books and stories very helpful to show him that others may get upset or angry in a particular situation. This helped him to understand what he was feeling.”

John and Teresa, parents of Jonathon (9) – Down’s syndrome
“I say, ‘I know you’re upset/angry/frightened.’ Alister will often calm down when I say this and come to me for a cuddle.”

Marie, mother of Alister (age 11) – Chromosome 18 q depletion – Main problems are moderate hearing impairment and autism

“Try using pictures (PECS) – there are pictures for all the emotions.”

Marie, mother of Alister (age 11) – Chromosome 18 q depletion – Main problems are moderate hearing impairment and autism

“Use Makaton to reaffirm a particular emotion, i.e. scared – show examples of a character in a book or television programme being scared.”

Dina, mother of Grace (age 3) – HDR or Barakat syndrome

“Using the NDCS excellent book on emotions. This is part of the national curriculum in Year 3.”

Annabel, mother of Freddie (age 7) – Down’s syndrome

“I always allow my child to express his emotions (in the appropriate environment). We have talked about it afterwards and discussed better ways to improve frustrations or emotions.”

Jayne, mother of Scott (age 9) – Hydrocephalus and learning difficulties

“I gave Natalie a diary for Christmas so that she could put all her thoughts down. Animals bring out the best in children. Also puppet gloves encourage them to share their feelings.”

Lesley, mother of Natalie (age 17) – CHARGE syndrome, partially sighted

“Body contact (i.e. a cuddle when frightened/hurt) and eye to eye contact can help children deal with their emotions.”

Colin and Marion, parents of Helen (age 5) – Learning difficulties and poor concentration

“Use happy/sad teddy bear puzzle to talk about emotions (Moody Bear). Trying to use the appropriate words in everyday situations, e.g. ‘see that little girl crying, she is sad,’ ‘you broke the ornament, Mummy is angry,’ ‘we are at the seaside, are you happy?’ etc. We try to use the appropriate words to express emotions at the time.”

Jeanette, mother of Aidan (age 7) – Severe learning difficulties and global development delay

“Read to them. Use drawing and mirror faces to help them to understand emotion (e.g. happy/sad etc.). Use puppets to express feelings and story telling. Children feel less threatened speaking to a puppet rather than an adult. Puppets can be silly! Repeating back his emotions to him when you read them, i.e. ‘David is smiling, he must be happy,’ ‘Libby is crying, she must be sad,’ etc.”

Peter and Delilah, parents of David (age 4)
Independence

Independence means different things to different children. It may mean learning to feed yourself, choosing what you want to wear or going on the bus by yourself. For parents the challenge can be to let children gain independence. Stepping into the unknown can be frightening for you and your child.

“As a working mother my child has attended a variety of clubs/ play schemes in the holidays and I think this has helped him to be confident with strangers. Despite his autism he is happy to be in the company of other people.”

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Marie, mother of Alister (age 11) –
Chromosome 18 q depletion –
Main problems are moderate hearing impairment and autism

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“It is slow and it is hard not to overprotect, but just letting them do little things that terrify you can give them a huge boost of confidence when they succeed, and to let them know you have faith in them.”

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Teresa, mother of Juliet (age 9) –
Leopards syndrome including heart disease

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“We always look out for things our son is good at, however unusual or unexpected, and help him to practise, and praise him. He takes great photos so has unrestricted use of my digital camera, which he hasn’t broken – yet!”

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Annabel, mother of Freddie (age 7) –
Down’s syndrome

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“I volunteered to run the sweet shop at Riding for the Disabled for the sole purpose of encouraging Natalie to help in the shop and learn to meet, serve and greet customers. Allowing Natalie to be in charge and make decisions on her own – however long it takes, and then congratulate her.”

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Lesley, mother of Natalie (age 17) –
CHARGE syndrome, partially sighted

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“Celebrate all the ‘small achievements’ as though they are ‘huge’ because they are really!”

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Eileen and John, parents of Carmel (age 17) –
Photosensitive epilepsy, anterior ectopic rectum, cerebral palsy, orthopaedic abnormalities, thyreotoxosis, horseshoe kidney with some loss of function
**Time for yourself**

All parents enjoy having some time to simply relax. When a deaf child has additional or complex needs, such time may be particularly difficult to find. Children may need help with feeding, moving or toileting, or have a complex medication routine or demanding behaviour. Sleep patterns may be very disturbed. Parents may feel physically and emotionally drained. Here parents underline the importance of making time for yourself and tell you how they managed it.

“I enjoy time to myself – asleep!”

*Carole, mother of George (20 months) – Down’s syndrome and low muscle tone*

“You should not feel guilty for relaxing when you can grab some time. In the afternoon for instance, book a massage and always say you deserve this. As someone once told me, ’you can’t give if you have nothing left, always take time to restock your energy levels.”

*Sally, mother of Ben (age 6) – Asperger’s syndrome*

“I have two hours free babysitting service from British Nursing Association services. Visit friends, go to the pictures or take a nice long walk.”

*Jayne, mother of Scott (age 9) – Hydrocephalus and learning difficulties*

“When taking time to ourselves we relax without the children needing supervision, take part in our hobbies and watch adult TV in peace.”

*Colin and Marion, parents of Helen (age 5) – Learning difficulties and poor concentration*

“I leave all the children with my husband for two weekends a year and go away on my own – ideally to a health farm. I save up every month over the year. The children live on junk food for the weekend but seem very happy to survive without me.”

*Annabel, mother of Freddie (age 7) – Down’s syndrome*

“Going out for a run or a walk. Visiting a museum or an art gallery. I can think of many things to do, if only I did get the time! Both of these activities can focus your mind on something other than your situation.”

*Donna and Simon, parents of Oliver (age 2) – Cerebral palsy, epilepsy and learning difficulties*

“Sit down with a cup of tea and watch TV uninterrupted, go out for lunch with friends, go to the cinema, go for a swim.”

*Marie, mother of Alister (age 11) – Chromosome 18 q depletion – Main problems are moderate hearing impairment and autism*

“Deep breaths, count to ten.”

*Jayne, mother of Scott (age 9) – Hydrocephalus and learning difficulties*
“Do something totally absorbing which allows you to switch off from everything – for me it’s gardening, exercise, card making, and sewing.”

Sally, mother of Ryan (age 8) – Ocular cerebral hypopigmentation syndrome

“Going out with friends and being able to relax and talk without constant interruptions or keeping one eye on the door, looking for potential danger.”

Jeanette, mother of Aidan (age 7) – Severe learning difficulties and global development delay

“As hard as it may be sometimes, try to remain calm. Evaluate the situation and talk about it afterwards. If possible and there’s another person around, ask for a break. You’re not being a bad parent.”

Dina, mother of Grace (age 3) – HDR or Barakat syndrome

“Callum is terminally ill as his kidneys have failed. Dialysis treatment was started when he was four but after eight months it had to stop due to an internal infection. Callum is not able to re-start dialysis as the infection would come back. He is also not suitable for transplantation, so as a result we are having as many days out as a family with Callum while it is possible. Although he is ill, he is very sociable and happy within himself, and we continue to sign to him as we know this is our way of communicating with him.”

Michael, father of Callum (age 5) – Athetoid Cerebral palsy and renal failure

Support from others

Parents have told us about many different types of support, both from their own family, other families and from services. Some of the most useful practical advice comes from other parents. As many families meet a range of professionals they share hints on how to get the most out of services for your child. Parents stress the importance of self-trust and of staying in charge of the situation.

“How hard as it may be sometimes, try to remain calm. Evaluate the situation and talk about it afterwards. If possible and there’s another person around, ask for a break. You’re not being a bad parent.”

Dina, mother of Grace (age 3) – HDR or Barakat syndrome

“When working with professionals take control and give yourself permission to be in charge. Allow yourself to have the day off. It is OK not to have an appointment for a day! Get professionals to talk to each other and do not become the liaison yourself. Once a term get all of the professionals in a meeting together with you present. All the points get collected and you can make sure you are all working towards common aims. The professionals will be very receptive once you suggest this. Get professionals to work in a way to suit you. For example, I use email; I can email them at night when George has gone to bed and get a reply the next day.”

Carole, mother of George (20 months) – Down’s syndrome and low muscle tone
“Go with your own instincts regarding your child’s health. Professionals always give a worst-case scenario. Go with your own belief as you know your child and live with him 24/7 whereas a professional sees the child only on occasion for half an hour.”

*Michael, father of Callum (age 5)* –
Athetoid Cerebral palsy and renal failure

“Try to keep a notepad handy in the house in order to write down on a regular basis things that will be discussed with professionals. You can’t always remember details so it is a good idea to keep a diary of events.”

*Sally, mother of Ben (age 6)* –
Asperger’s syndrome

“Try and keep them all up-to-date with each other. Don’t put them on a pedestal; they are only doing a job. Don’t be frightened to ask questions. Ask for help or be referred to others.”

*Colin and Marion, parents of Helen (age 5)* –
Learning difficulties and poor concentration

“Be confident with them. Most have been helpful but I have found it distressing if they had not read the notes before seeing me and her.”

*John and Rosemary, parents of Susannah (age 24)* –
Multiple disabilities

“Keep a file with all letters from professionals, so if they ask for names, etc. it’s all together. Ask professionals questions – tell them what works and what doesn’t. Seek help from local services, eg Sure Start.”

*Jayne, mother of Scott (age 9)* –
Hydrocephalus and learning difficulties

“Be armed with knowledge if you can. Question fully, don’t be fobbed off, trust your intuition. Stand your ground. Ask ‘why not?’ and expect a sensible answer.”

*Eileen and John, parents of Carmel (age 17)* –
Photosensitive epilepsy, anterior ectopic rectum, cerebral palsy, orthopaedic abnormalities, thyreotoxicosis, horseshoe kidney with some loss of function

“Be prepared. Take a list of questions with you. Be yourself, be friendly. They are just normal people who may be able to help.”

*Sally, mother of Ryan (age 8)* –
Ocular cerebral hypopigmentation syndrome

“Always remember that you are the expert on your child and that professionals often have very narrow areas of expertise. Be assertive when dealing with professionals and don’t be afraid to question their advice. Listen to what all professionals have to say and then make your own mind up about whether to act on that advice. Be wary about professionals giving advice/opinions outside their area of expertise, e.g. educational professionals giving health advice and vice versa.”

*Marie, mother of Alister (age 11)* –
Chromosome 18 q depletion –
Main problems are moderate hearing impairment and autism
“Remember you know your child better than anyone. Have the courage to say no. Don’t accept the ‘tried and tested’ if you are convinced it’s not right for your child.”

Carol, mother of Charlie (age 14) – Attention Deficit Hyperactivity Disorder, and a language disorder (no specific name given yet)

“Don’t be intimidated. You know your child better than they do. They are humans with lives too and everyone’s goal should be the best for your child.”

Teresa, mother of Juliet (age 9) – Leopards syndrome including heart disease

“Always question them on any issues you dispute or do not understand. Use them as a resource, build a good relationship with them and remember that you are the expert on your child’s ability.”

Norma, mother of Conor (age 10) – cerebral palsy and diabetic

“Other parents of special needs children will be happier to let you talk about your feelings and will understand better than parents of non-disabled children.”

Sally, mother of Ryan (age 8) – Ocular cerebral hypopigmentation syndrome

“Meeting other parents can and does help. However, just because you have this in common doesn’t necessarily mean your outlooks will be similar.”

Donna and Simon, parents of Oliver (age 2) – Cerebral palsy, epilepsy and learning difficulties

“George did not sit up as early as other children. It is very hard to sign to a child who is lying on the floor. You need eye contact; it makes signing so much easier. The other problem is with hearing aids, they whistle constantly if your child is always lying down. The occupational therapy department lent me a specially designed chair, which allowed George to be strapped in so I could sit him up and keep my hands free to sign to him. It also meant his hearing aids were less likely to whistle.”

“When we were experiencing sleep problems with George I found cerebra.org.uk very helpful. They employ a sleep nurse who helps you deal with sleeping problems for children with learning and hearing difficulties.”

“The charity Home Start provides respite care for me three hours a week. A volunteer comes around and plays with George so that I can leave the room and get on with other things I need to do.”

“Britax make a great pushchair which enables you to face a child backwards in the seat, so that they can see you signing whilst walking. You can use this chair for children up to four or five years of age which is great for children with additional needs who can’t move about well.”

“We have found out more through parents than any other source, e.g. Continence Service, Special Needs Swimming, Riding for the Disabled, Crossroads, etc.”

Jeanette, mother of Aidan (age 7) – Severe learning difficulties and global development delay

Resources

Parents have told us about the resources that they have found helpful. These range from information sources on websites to local or regional special activity groups and local clubs. You can find local information at the library, parents support groups or the social services department.
“‘Gymbobs’ was very good for Aidan.”
Jeanette, mother of Aidan (age 7) – Severe learning difficulties and global development delay

“‘CLIMB’ (www.climb.org.uk) was useful. ‘Contact a Family’ was very good.”
Dina, mother of Grace (age 3) – HDR or Barakat syndrome

“These were very good, and we’ll try ‘Treehouse’ too.”
Jeanette, mother of Aidan (age 7) – Severe learning difficulties and global development delay

“Think About Being Deaf by Maggie Wooley, I’m Deaf And It’s Okay by Lorraine Aseltine, Evelyn Mueller and Nancy Tait.”
Teresa, mother of Juliet (age 9) – Leopards syndrome including heart disease

“We joined local group, ‘Horizons’ for children/parents with all disabilities. ‘Face Us’ organisation in Basingstoke for hearing impaired children/parents/carers is also useful.”
Jayne, mother of Scott (age 9) – Hydrocephalus and learning difficulties

“I attended the National Autistic Earlybird course which helped me deal with Ben’s emotions. I believe Ben is in touch with his emotions and those of others because we spent a lot of time explaining to Ben what he was feeling when he was happy. We would also tell him when he was sad. I believe he understands other people’s feeling and emotions because we taught him his own feelings.”
Sally, mother of Ben (age 6) – Asperger’s syndrome

“Ask your local social services department if there are any courses for parents on dealing with ‘Challenging Behaviour.’ I recently attended a parent’s course for dealing with challenging behaviour and I am no longer afraid of being alone with my child.”
Marie, mother of Alister (age 11) – Chromosome 18 q depletion – Main problems are moderate hearing impairment and autism

“SENSE, RNIB Holidays, Dorton Home Holidays, The Church, Guides, CHARGE Association, Trampoline Club, Scuba Diving Club, Riding for the Disabled.”
Lesley, mother of Natalie (age 17) – CHARGE syndrome, partially sighted
Other NDCS resources

NDCS has produced *My weekly planner* which many parents have told us they find invaluable. The wipe-clean magnetic board is used to help take the stress out of explaining to deaf children what activities or appointments they are taking part in. Contact the NDCS Helpline if you think one might be useful to you.

We have a range of films taken from the Big Weekend. The films are for parents and give ideas for resources for your deaf child with additional needs. The films cover the following topics:

- creating a sensory experience
- creating a safe space
- creating safe toys
- where to buy safe toys
- creating exciting sounds
- creating sensory stories.

**Other NDCS publications:**

- *Genetic Counselling – Information for families*
- *A Child with Microtia and Atresia*
- *Meningitis and Childhood Deafness*
- *Congenital Cytomegalovirus and Deafness*
- *Enlarged Vestibular Aqueducts*
- *Balance and Balance Disorders*
- *Cleft Palate and Childhood Deafness*
- *Bone Anchored Hearing Aids*
- *Cochlear Implants*
- *Hearing Aids*

*Complex Needs, Complex Challenges* is a research report into the experiences of families with deaf children with additional complex needs. The report was funded by NDCS and undertaken by the University of Manchester.

NDCS local groups and other families can offer useful and valuable information and advice. Their views and experiences can help you to feel that someone understands your situation. You can contact local groups through your local library, health visitor, local nursery, telephone directory, the internet or by contacting a national organisation and asking for local contacts.

You can share concerns, positive stories or talk about something completely different. You can find out about local toy libraries, babysitting services and childminders, local schools and places that are child friendly.

**Useful organisations**

**Contact a Family**
Contact a Family is a UK-wide charity providing advice, information and support to parents of disabled children. They produce a book and online information relating to a range of syndromes and conditions, both common and rare. Contact a Family can put parents in contact with other families, on a local and national basis.

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)
Phone: 0808 808 3555
Minicom: 0808 808 3556

**Information Exchange**
A small, user-friendly magazine written by, and for, people working with or living with children who are deaf, blind or deafblind and also have severe learning disabilities.

Email Saracer@aol.com

**Netbuddy**
Netbuddy is an award winning site for swapping practical tips and information on all aspects of supporting people with special needs.

Website: [www.netbuddy.org.uk](http://www.netbuddy.org.uk)

**Disabled Living Foundation**
Website: [www.dlf.org.uk](http://www.dlf.org.uk)
Phone: 0845 130 9177

**Education and resources for improving childhood continence** (control of the bowel and bladder)
Website: [www.eric.org.uk](http://www.eric.org.uk)
Phone: 0845 370 8008

**ACE (Advisory Centre Education)**
Website: [www.ace-ed.org.uk](http://www.ace-ed.org.uk)
Phone: 0808 800 5793

**Disability Living Allowance and Carer’s Allowance**
[www.direct.gov.uk](http://www.direct.gov.uk)

**Tax Credits**
[www.hmrc.gov.uk/taxcredits](http://www.hmrc.gov.uk/taxcredits)
Family Fund
www.familyfund.org.uk
info@familyfund.org.uk

• Resources for daily living including local carer centres, parent partnership services and dialability (a free service that provides information on transport, equipment and access to leisure).

• Short-break care through social services and the children’s assessment team. Short breaks may be organised with another family, a local specialist-care facility or a resource run by an independent group of trustees.

• Home equipment. Depending on a child’s needs, a range of professionals may be involved in providing equipment. This may include specialist feeding, bathing and handling equipment as well as hearing aids and radio aids.
NDCS provides the following services through our membership scheme. Registration is simple, fast and free to parents and carers of deaf children and professionals working with them. Contact the Freephone Helpline (see below) or register through www.ndcs.org.uk

- A Freephone Helpline 0808 800 8880 (voice and text) offering clear, balanced information on many issues relating to childhood deafness, including schooling and communication options.

- A range of publications for parents and professionals on areas such as audiology, parenting and financial support.

- A website at www.ndcs.org.uk with regularly updated information on all aspects of childhood deafness and access to all NDCS publications.

- A team of family officers who provide information and local support for families of deaf children across the UK.

- Specialist information, advice and support (including representation at hearings if needed) from one of our appeals advisers in relation to the following types of tribunal appeals: education (including disability discrimination, special educational needs (SEN) and, in Scotland, Additional Support for Learning (ASL)); and benefits.

- An audiologist and technology team to provide information about deafness and equipment that may help deaf children.

- Technology Test Drive – an equipment loan service that enables deaf children to try out equipment at home or school

- Family weekends and special events for families of deaf children.

- Sports, arts and outdoor activities for deaf children and young people.

- A quarterly magazine and regular email updates.

- An online forum for parents and carers to share their experiences, at www.ndcs.org.uk/parentplace.

- A website for deaf children and young people to get information, share their experiences and have fun www.buzz.org.uk.
NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

NDCS Freephone Helpline: 0808 800 8880 (voice and text)

helpline@ndcs.org.uk

www.ndcs.org.uk