



Helping you choose: making informed choices for you and your deaf child

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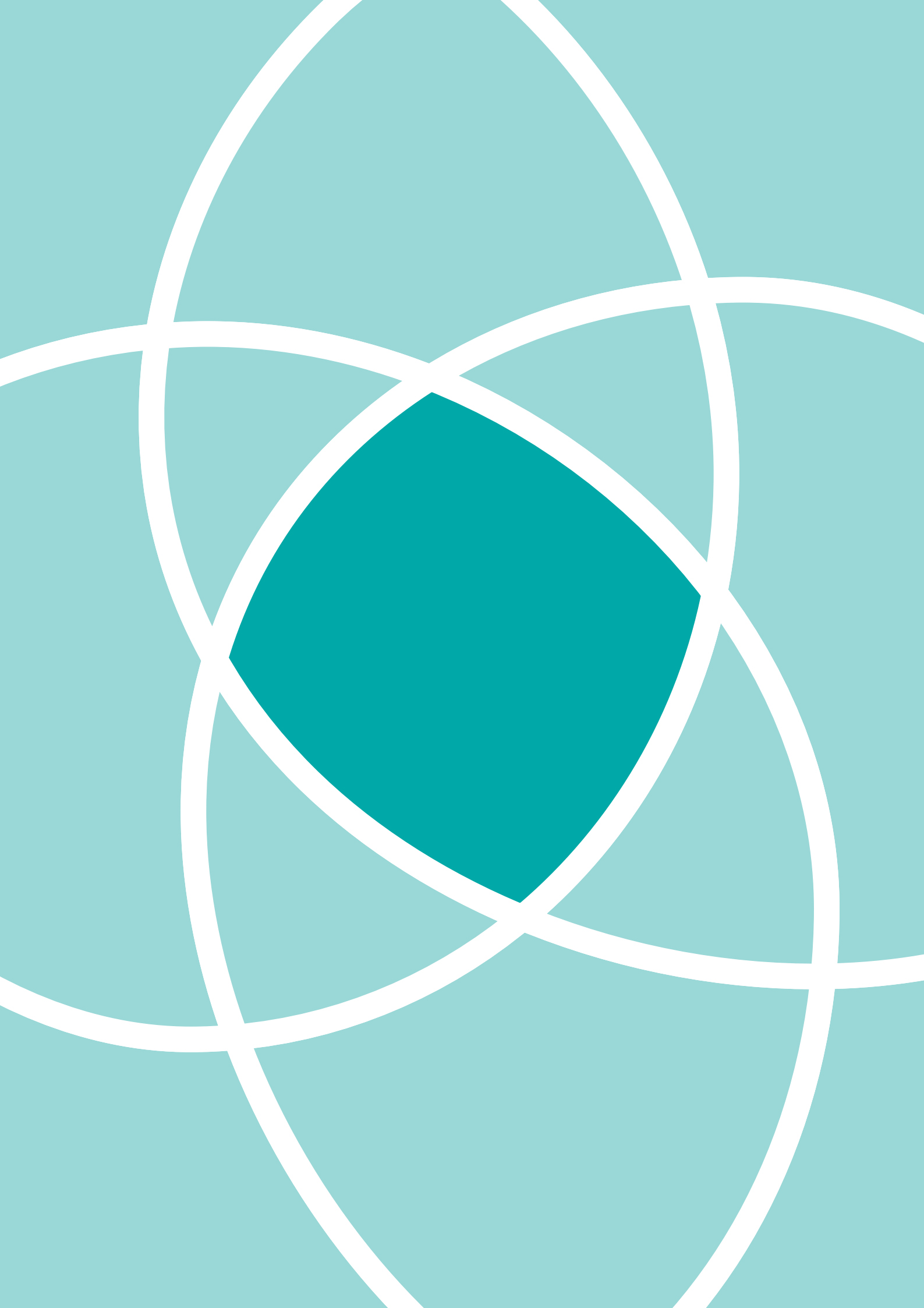
Early Support

Helping every child succeed

Helping you choose

Making informed choices
for you and your child







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About this publication

This publication was produced for [Early Support](#) by The National Deaf Children's Society (NDCS) and The University of Manchester, in consultation with families and professionals who work with families. It explores the concept of 'Informed Choice' in relation to the decisions that families take about, and on behalf of, young deaf children.

Companion material for professionals has also been developed. The professional handbook *Informed choice, families and deaf children* explores similar issues from the perspective of professionals. If you would like a copy of the material for professionals, please ring 0845 602 2260 and ask for the publication using the reference number ES46.

In this booklet:

[Section one](#) describes what Informed Choice is.

[Section two](#) gives descriptions of different aspects of Informed Choice to think about. With these are examples of situations that some families have been in, and details of the various services and support networks they were involved with. Details of what the examples show and what can be learnt from them about Informed Choice follow.

[Section three](#) outlines what to expect from services who offer Informed Choice. There is a list of key questions to ask professionals to make sure you are being given the opportunity to make informed choices.

Throughout this booklet the term 'deaf' is used to refer to children with all levels of hearing loss. You may use a different term to describe your child's hearing loss. Some of the other common terms that are used are 'hearing impaired', 'hard of hearing', 'partially hearing' and 'partially deaf'. In this booklet, 'deaf' is used to include all of these. When Deaf (spelt with a capital 'D') is used, it refers to people who consider their deafness to be a major factor in their cultural identity.

This publication is also available in British Sign Language. To order a copy on DVD, ring 0845 602 2260 or text 0845 605 5560, using the reference number ES48.

Section one

Introduction

This booklet is about 'Informed Choice'. This may sound very straightforward. Surely it just means 'Have I been informed?' and 'Have I been offered a choice?' Those two things are important, but there are many other issues to think about.

The aim of this booklet is to help you to understand and think about questions like:

- Am I getting the right sort of help and support to make choices and decisions that I'm happy with and that are right for my family?
- Am I being offered all the choices and opportunities that are available for deaf children and their families?
- Do I feel I'm being treated with respect and are my views and opinions being valued?

Families were involved in the creation of this material. It was parents like you who told us what was important for them, what they thought helped them to make informed choices and what prevented them from making informed choices.

The booklet discusses some of the key issues around how Informed Choice can help you make the right decisions for your deaf child and family. The examples in [Section two](#) share solutions that worked for some families. They may or may not work for you in your situation.

Read more about this in [How this material was produced](#)



What this booklet tries to do is show the different ways in which professionals and services can make sure you have Informed Choice. It isn't possible to list all the possible choices that could or should be offered to you as parents or carers of deaf children. What you need to do is to think about what would suit you – the practical examples are included to help you to think creatively about what's right for you and your family in your situation.

Some of the names or terms used may be new to you or they may be different ways of describing things that you already know about. Many of the terms used are explained in more detail in another Early Support publication – the Information for parents booklet on *Deafness*. You might find it helpful to refer to it as you read through this material. If you don't have a copy, ask a professional who works with you regularly about it, or ring 0845 602 2260 to ask for one – it's free.

Throughout this booklet where words are written in this colour, you can find more information by looking in the *Deafness* booklet. Footnote numbers that are given at the bottom of the page, refer to the relevant page numbers of the *Deafness* booklet. The example below tells you that a description of ' earmoulds' can be found on page 48 of the Early Support Information for parents booklet on *Deafness*.

Example:

Your child may have earmoulds¹ fitted

¹ page 48

What does Informed Choice mean?

As a parent or carer of a deaf child, you have to make a range of decisions about your child. These might be about hearing aids, communication, choosing a nursery or other things. There are many new areas to think about, and most families don't start out knowing a lot about deafness. You may meet many service providers, such as a teacher of the deaf, an audiologist, a consultant at the hospital or a social worker for deaf children. They're the ones who are likely to tell you about the different choices that you can make for your child and for yourselves. But they may not be able to give you all the answers!

In the past, the kind of information you would have received depended very much on where you lived. It's still true today that different types of services are available in different areas, and that parents are offered different choices in different ways. This booklet is trying to help you think about whether you're being given full information, whether you're getting the right kind of support to make decisions and what you can do to make sure you're being offered Informed Choice.

Have a look at this example of a family situation:

John and Afeefa's second child, Tom, is deaf and is three months old. There has never been anyone deaf in either of their families before. Tom already has [hearing aids](#)¹ and is communicating well. His parents are starting to think about how they'll develop communication with him in the future. They recently met another hearing family with a deaf child, who is now four. The other parents advised Afeefa and John to pick a [natural aural approach](#)². Their [teacher of the deaf](#)³ has suggested that they might want to think about a [sign bilingual approach](#)⁴. The hospital is also suggesting that they consider giving Tom a cochlear implant and having [auditory verbal therapy](#)⁵. Afeefa and John feel at a loss as to what decisions they should make.

¹ page 39

² page 70

³ page 14

⁴ page 73

⁵ page 71



By Informed Choice, we mean that Afeefa and John should have good information about all the options available, not just about what other people think is best. They should feel confident that they understand the information they've been given. Understanding the information includes understanding what each of the choices might mean, both now and in the future, for their child and for their family. They may want to reconsider their decisions at a later date as Tom grows, as they learn more, or as their situation changes. They should feel that they're supported by the professionals working with them, whatever decisions they make. Above all, they must be comfortable about their choices, knowing they've taken good advice, weighed up the options, and reached their own decisions.

Choices can be about a number of different things for you and your deaf child. The types of issues that come up include:

- types of amplification
- methods of communication
- making appointments work for you
- school provision
- suitable support networks
- levels of information.

You may feel worried that you're going to make a 'wrong' choice. This is why you need to make sure that you know as much as you need to know about all the options available. Many choices change naturally over time. What may feel like a 'wrong' choice further down the line is likely to have been the 'right' choice at the time you made it.

Sometimes you might feel happy with how things are progressing for your family, but you simply want to know more about other possibilities. Informed Choice is not just about making choices. Feeling confident that you know everything you want to know about different options is an important part of what it means to be offered Informed Choice.

Let's look at John and Afeefa again:

Afeefa wanted all the information she could possibly get, as it made her feel secure to know she could go back to it whenever she wanted. John was feeling overwhelmed by everything.

The teacher of the deaf has passed on lots of information to Afeefa. The teacher has also talked to John about what he's most worried about and tried to help him pick out the materials most relevant to his concerns. She always listens carefully to the family and supports them in the choices they'd like to make. She has also provided some resources about all the different communication options. In these you can find out about older deaf children whose parents have made particular choices and how they've got on. Tom really liked having different types of information, as he could go through it as many times as he wanted and in his own time.

Afeefa's parents live very near and are very involved with Tom. They'll be providing childcare when Afeefa goes back to work, so the choice of communication is very important to them too. As English is not Afeefa's parents' first language, the teacher of the deaf has given them some materials in Urdu and a video with subtitles. She's visited the family when Afeefa's parents and best friend have been able to be there and Afeefa knows that her parents could have an interpreter if they wanted.

John and Afeefa know that when they feel ready, the teacher of the deaf will arrange for them to meet some other families who've made different choices. Although it's a long way off, they have been asked if they would like to visit the nearest nursery where they use sign language and have regular visits from deaf adults, as well as other places offering different services, so they can see what making different choices would be like for them.

The [Cochlear Implant](#)⁶ Centre has made sure that the whole family have received information in appropriate languages about cochlear implants. They video their consultations, so that Afeefa can take the film home and watch it again, as she feels that she can't take everything in during appointments. Above all, Afeefa and John feel that all the professionals they have met have listened carefully to them, valued what they have to say and not tried to encourage them to make one choice rather than another (although John sometimes thinks it would be easier if they did!).

⁶ page 56



Section two

This section is to help you think more about what Informed Choice may mean for you, your child and the rest of your family. It sets out lots of examples of different family situations and the sorts of things that make it easier or more difficult to make informed choices.

After each example we have put some ideas about things that you might ask about or things you might do if you were in a similar situation. These are just ideas – you are best placed to think of things you might want to do that fit in with your family better. When you read the examples, you may want to think about what similar situations might be like for your family, choices you might want to make, or how much choice you've already been offered.

Every family is different

Every family and every family situation is different. You're the person who knows your family best. The choices that other families make may not suit you and your family. You need to make choices that are right for you. Families make different choices for all kinds of reasons – it may be because of their different personalities, situations, beliefs, values, religions, cultures, backgrounds or ways of life.

After **newborn hearing screening**⁷ Sue found out that her third child, Jenny, was deaf. Sue is beginning to explore different ways of communicating with Jenny. She's read a lot of information, seen a video and talked with her visiting teacher of the deaf, but she finds it hard to imagine what any of the options she's found out about might be like for her, as a single mother.

⁷ *Newborn hearing screening is a simple test which identifies babies who need further testing on their hearing.*

The teacher of the deaf has arranged for Sue to meet two other mothers and their children. One of the families has chosen a [sign bilingual route](#)⁸, and the other family has chosen an [auditory verbal approach](#)⁹ to communicate with their child.

Sue finds it really helpful hearing their stories and meeting the children, who are both four year olds and developing really well. On the other hand, both the other families are in very different situations to her. They're professional, two-parent families with lifestyles that are very different from hers. Although she can see that the choices they've made work for them, she can't imagine how they would work for her.

What helpful things can be learnt from Sue's story?

- Choices that suit other families may not suit your family.
- It can be helpful to explore the ways in which your child and family are similar to others as well as the ways in which your child and family are different from others.
- Choices you make must fit in with your family's way of doing things if they're going to work for you. As time goes by, this may change.
- It might help you to draw up a list of pros and cons for options you are thinking about.
- Ask a number of people why they have or have not made certain decisions. You could meet them through The National Deaf Children's Society family supporter network.
- Spend time talking about and deciding what's important to you, your deaf child and your whole family.

Find out how to
contact NDCS at the
back of the booklet

⁸ page 73

⁹ page 71



I know my family and child best

As a parent, you're the one who knows your family situation and child best. Although professionals have lots of expertise about deafness and deaf children, they're unlikely to know your child as well as you do. It's important to remember that in many situations, the choices you make for your child and family need to be based on your knowledge as a parent, rather than on a professional's knowledge of deafness. For some difficult decisions, you may feel you want to rely more heavily on professional expertise, as well as your own knowledge of your child and family.

Theo is 16 months old, is deaf and has cerebral palsy. He's going to a nursery with hearing children two mornings a week. The possibility has come up of going to the nursery for four full days per week. The [social worker](#)¹⁰ suggests that this is a good idea because the family could do with a break. She thinks it would also help Theo to develop more spoken language and learn by mixing with other children. Theo's mother knows that the social worker is trying to be helpful, but she disagrees. She speaks with her teacher of the deaf about the matter and makes the decision to keep Theo at nursery for two mornings a week. She feels he's doing well at the moment, but is still too young to cope with four days a week and needs to spend time getting to know all the professionals who work with him because of his cerebral palsy. After talking to her health visitor and sharing her concerns, Theo's mother decides to increase his nursery attendance half a day at a time. She feels strongly that Theo is benefiting from being at home with his other brother and the rest of the family.

¹⁰ page 15

What helpful things can be learnt from Theo's mum's experience?

- Don't be afraid to say what you think and what you know.
- Don't be afraid to trust your instincts as a parent.
- Professionals can help you make your thoughts and feelings clear.
- Sometimes it's helpful to use another person to explain what's important for you and your family. This could be a family member, a supportive professional, a friend or an advocate.
- Charting your child's development can help you make more informed choices. Some families like to use the *Early Support Monitoring protocol for deaf babies and children* to help them to do this.

Read more about
this at the end of
the booklet

I need more than information to make a choice

Having lots of information is an important part of making choices for your deaf child and family. Sometimes you may feel that you haven't been given enough information. Or maybe you've been given too much information and feel overwhelmed. Maybe the information you've received is unhelpful or you don't understand it all yet. Some parents like reading information, others want to have it explained and discussed or to experience different options for themselves. It's part of the job of the professionals who work with you to help you understand the information you've been given, to ask questions about it, and to get the experience you might need to make sense of it.



Amir and Habibah have read a lot about the **natural oral approach**¹¹. Before they decide if this is right for their daughter, Shazia, they want to meet another family, with a slightly older child, who have chosen this communication approach. They want to know what it would be like for them in real life, and to hear about the other family's experiences. Although they know that no two children are the same, they feel that only then will they have an idea of exactly what this approach involves and whether it would be a good choice for Shazia. Amir's mother, Shazia's grandmother, who looks after Shazia during the day, wants to know about the pros and cons of different choices. She's asked how they know whether the information they've received so far is trustworthy.

Amir and Habibah have not really thought about these questions, and wonder where they should go to try and get answers.

Everyone, including grandma, goes on a parenting weekend for families of deaf children. Amir finds it extremely useful and enjoys it greatly, but Habibah would have preferred more structured opportunities to talk with people one-to-one.

What can be learnt from Amir and Habibah's experience?

- Not all families want information in the same way.
- Make sure you're getting the right kind of information about the things you want to know.
- Try the library, the internet and agencies such as The National Deaf Children's Society to get a range of information and different points of view.
- Ask questions until you're confident that you understand.
- Take time – don't be rushed into things.
- Meet other parents.

¹¹ page 70

- Meet older children whose families have made different choices.
- Meet deaf adults and find out what they think.
- Ask what the advantages and disadvantages of different options might be.
- Ask to visit a nursery or school where there are deaf children to see how those children are getting on.

Do I really have a choice in every situation?

Some things are presented to you as if there is no choice – but in reality there's choice about almost everything. For example, you may feel that the appointments you've been given are not a good use of your time and so perhaps you will choose which are most useful to you.

The Evans family have just been told that their three-month-old daughter, Lauren, is deaf. Her deafness was identified following newborn hearing screening. The family's audiologist¹² strongly suggests that Lauren be fitted with hearing aids¹³. What they want to know is whether Lauren has to have hearing aids straight away. They've heard other parents saying that it can be very difficult with a small baby. They would rather enjoy her as she is and think about hearing aids later. They want to know if this is something they'd be allowed to have choice about.

Due to staff changes in social services, the Fletcher family have a new social worker visiting them. Their son is deaf and has multiple disabilities. The family are becoming more and more frustrated, because the new worker has limited experience of deaf children, whereas the one before was very experienced. The family would like to ask for a different social worker, but don't know how to do this, or if this is possible. At the same time they don't want to upset anybody.

¹² page 11

¹³ page 39



What helpful things can be learnt from these families' stories?

- It's all right to question why you have not been offered a choice about something.
- If you feel that a particular professional is not offering a quality service, you are free to ask for someone different.
- It might be a good idea to talk an issue over with a professional you know and trust before deciding what steps to take.
- If you want to challenge some aspects of the services you're receiving you might want support from an independent individual or organisation – for example, an advocate or The National Deaf Children's Society.
- Make sure you know about the risks and benefits of any choices you might be making. You may want to talk to another professional or someone independent from your local services.

It seems like the professionals think one choice is better

Sometimes professionals have strongly held views. Even when they're open and honest about them, this can be confusing. Also, the way in which your local authority or health service spend their money might give the impression that some kinds of service are better than others – more money is spent on them and more positive sounding information is given out about them.

Penny and Doug's fourth child Emily was diagnosed as profoundly deaf after being born eight weeks premature. She's now five months old and has had hearing aids fitted. The family have regular meetings with the teacher of the deaf and they've also met a specialist social worker with experience of deaf children. They find that all the professionals they've met have been helpful and supportive. They have given them lots of relevant information, and responded to all their questions and requests.

The problem is that they feel they really need to decide on which communication method or methods they want to focus on as a family. One of the professionals very strongly supports an [oral approach](#)¹⁴. The other is a strong advocate for the use of [sign language](#)¹⁵. Both have tried not to impose their views, but nevertheless their different opinions are very clear. Penny and Doug appreciate the passion and commitment that each of them is showing, but are amazed that there is such strong disagreement among the people they come into contact with.

Penny and Doug are also aware that their local authority puts most of its resources into services for children using an oral approach. They feel that this must surely mean that this option is better. However, they recently met another hearing family with a deaf child who lived in a neighbouring authority where most of their resources were used to support children using a [sign bilingual approach](#)¹⁶.

They're totally confused by this. Penny asks about the research that has been done on the different outcomes for children whose parents choose different approaches. She wants to know about what different choices will mean for Emily's education in the future and how she'll develop socially and emotionally. Both professionals tell her that there are no conclusive research results.

¹⁴ page 69

¹⁵ page 73

¹⁶ page 73



What helpful things can be learnt from Penny and Doug's experience?

- It might be helpful to find out why professionals think as they do – is it based on evidence, or is it bias?
- There aren't always definite answers to questions – sometimes things just are uncertain.
- When you're finding out new things, it's normal to feel confused for a while. This is part of making choices.
- Different families are affected by different factors that persuade them to choose different options.
- You may need to ask whether it's possible to change the professional working with you if their opinion clashes with what you think and the choices you make and you feel this interferes with your working relationship with them.
- If your choice is not supported by your local authority, make sure there will be enough available support for your choice. This may involve challenging routine provision in your area.

I don't feel comfortable and confident about making choices

Making choices can be really difficult. Some people have more experience of it than others and different people do it in different ways. The choices you're being asked to make for your deaf child may be about things you've never had to think about before. It may take you some time to feel that you know how to make the best decisions for your child and family. If you need more time, more information or more help in making choices for your child and family, the professionals working with you should support you in this.

Colin and Beth's first child Adam, has been identified with a mild to moderate **conductive hearing loss**¹⁷. He also has epilepsy. Adam is now 10 months old. It's taken some time to arrive at a firm diagnosis and to establish what the situation is.

The audiologist has taken time to explain the advantages and disadvantages of Adam being fitted with hearing aids. She has explained that many children with a hearing loss like Adam's benefit from wearing hearing aids but she understands that Colin and Beth have concerns about his epilepsy which are a higher priority for them at the moment.

Now Colin and Beth are being asked to decide what they would like for Adam. They're frightened and anxious as they feel that this is the biggest decision they've ever had to make. They don't feel confident. They don't understand why, if the audiologist is the expert, she doesn't just tell them what to do. They feel that they have to tell people what they've decided at the next appointment.

What helpful things can be learnt from Colin and Beth's experience?

- It's important to focus on what you want for your family and your child.
- It may be possible to try something out, and then change your mind if it doesn't seem right for your child.
- It might be good to meet another family who've recently been in a similar situation.
- Talking with other professionals might help you get a different perspective on things.
- You could contact a local or national organisation such as The National Deaf Children's Society to talk through the issues.
- Don't be afraid to tell professionals that you need more time, or that you don't want any more information or advice until you've had time to think about it more.

¹⁷ page 22



It's OK to change my mind

All parents want to make the choice that's best for their child and family, but what your child and family need may change with time or with your increasing knowledge and experience. Decisions you make do not need to be set in stone. Over time you may need to change them. Perhaps you made choices several months (or even years) ago that you were happy with at the time, but now your child is older and has developed, you know more about other options and you'd like to make a different choice based on your changing needs. Perhaps you feel a choice you made just isn't working out. Changing choices is OK, but some choices are more difficult to change than others. The professionals working with you should support you in the process of making choices and support you in the choices you have made, even when you change your mind.

Jacob became deaf aged 10 months through meningitis and although the professionals felt it was important to arrange a quick referral for a cochlear implant assessment, his family didn't want to pursue it at that time and decided to follow a **total communication**¹⁸ approach. After several months of using total communication, the family wondered whether a sign bilingual approach might be better for him. Having discussed the idea with their teacher of the deaf they made a request to meet a Deaf adult who used sign language. The local authority was part of the NDCS Deaf Role Model scheme and so it was arranged that David, who is Deaf, would visit them once a week. David helped them all to learn signs that they can use with Jacob and told the family about Deaf culture. All the family members are happy with their new choice and feel it's the one best suited to their family at this time, although they'll carry on reviewing all of the options as Jacob grows. They've recently met with the Cochlear Implant Team to discuss options.

¹⁸ page 76

What helpful things can be learnt from Jacob's story?

- Value your own knowledge and experience.
- Make time to consider whether previous choices still feel right for you and your family.
- Talk things over with other family members.
- You may want to ask your keyworker or another professional to help you re-evaluate some of the choices you've made.
- Consider whether this is the right time to look at other options which you haven't thought about previously.
- Don't blame yourself if a previous choice now seems to have been wrong. You made the best decision you could at the time.
- Monitor your child's development with the professionals who support you, talking about what this means for choices in the past, present and future.

It's not readily available, but I still want to know about it

Just because something isn't available doesn't mean that you shouldn't know about it or that you can't have it. You may have been told that what you want costs too much or that the professionals don't have the right skills. Or there may be no staff available to provide a particular service. Whatever the reason, it's still helpful to be told about options, because only then can you decide what the best choice is for your child. You may find that you want to push for a service that isn't usually offered – that is your right. Providing all kinds of services can create real problems for professionals. Finances are limited and there is a shortage of some skills. But, it's still OK to want an option for your child and you should still be supported in your choice.

*The Early Support
Monitoring protocol
for deaf babies and
children can help you
to do this*



Carmel is six years old, profoundly deaf and attends the local mainstream school with a hearing impairment unit. She has been wearing hearing aids for a few years but she's starting to really struggle at school. Carmel's parents have met other parents of deaf children, some of whom have chosen to have their children fitted with cochlear implants. All of them are very pleased that they made this choice and have recommended that Carmel's parents look into doing the same thing.

Carmel's dad has found out about cochlear implants on the internet and they decide that at their next visit to their ENT consultant they're going to ask if they can start the assessment process. When they meet with him however, he tells them that the health authority, who fund the assessment and fitting procedures, have spent their budget for this year and so there's no point him making a referral. The earliest the family could possibly be referred would be the following April, when the health authority will be given more money. Carmel's parents are not happy with this decision, as they think having a cochlear implant fitted would really benefit Carmel. They spend a lot of time writing letters to their health authority and their local MP contesting it.

After a few months the health authority agree to make a special case for Carmel and she starts the assessment process. The family are aware that they are 'jumping the queue' and that money from next year's budget is being used on them, which may mean that another child will miss out. Other parents who are members of the local deaf children's society tell the health authority that this is unfair and provides unequal treatment. The health authority finally agree that they will increase the budget for fitting cochlear implants, so that more children in their area can be fitted every year and not have to wait so long.

As with Carmel's family, if you decide you want special treatment for your child that is not usually available, this can have both good and bad effects for other families. But, your responsibility is to your child and family and you should be supported in your choices.

What helpful things can be learnt from Carmel's story?

- Do I only want to know about what is available locally, or should I find out about what is happening elsewhere in the country?
- Would I like to know more about why the Children's Services/LEA/health authority/Children's Trust have chosen to provide the services they have? For example, maybe it's because it matches the skills of the professionals they employ, or it's a decision based on research or funding?
- If you are considering contesting a decision, think:
 - How strongly do I feel about this issue? Is it something I want to put my time and energy into fighting for?
 - Do I need support or an advocate to help me take the issue further? Is there a local parents group that could support me?
 - Is there a realistic chance of achieving my goal?
 - Could I take the matter to my local councillor?
 - Could I consider taking a really big step such as moving to another area which does provide the service I want?



Not everything I've been told about is available

Having decided on a preferred choice for your child, it can be frustrating to find that this particular option is not available in your area.

The Meir family who are Deaf and use **British Sign Language (BSL)**¹⁹ thought they would like to have the support of a speech and language therapist for their daughter, Hannah, who is three years old and also deaf. They are concerned about her developing speech, as well as BSL. However, they're disappointed to find out that there are no speech and language therapists in their area who have a qualification in working with deaf children.

From what they have heard, the Clarke family likes the **total communication**²⁰ philosophy. They think it would be most appropriate for their son Ryan, who has a severe hearing loss. However, it's not available where they live as their local area say their particular strength is in supporting a **natural aural approach**²¹.

Even when a particular option is not available to you and your deaf child, it's important that the professionals working with you are up front and honest about the range of options that exist, as well as those that are actually available in your local area. Sometimes options are not offered for a practical reason – for instance, there just aren't enough professionals with the right skills. Sometimes options are not on offer because of a policy decision by the local authority or the hospital trust. If you want to pursue a particular option, it might be important to find out why services are as they are and then you can seek help and advice to follow it up.

¹⁹ page 73

²⁰ page 76

²¹ page 70

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Have a look at how the Meir and Clarke families' dilemmas were resolved:

Although the Meir family found out that there were no specialist speech and language therapists (SLT) working in their area, they decided to try to find a solution. They contacted the head of the local speech and language service and spoke to the hospital management. The service arranged for a specialist speech and language therapist from another region to come and assess Hannah and set out a structured support programme for her that other SLTs could follow. Local staff also volunteered to go on a training course about working with deaf children.

The Clarke family discovered that total communication was not available in their local area. They even considered moving to a location where total communication was easily available. Then they discovered that it was an option in the next authority, so it was agreed that Ryan could attend nursery there, and that the local services would develop their skills in total communication so that the family could have their choice supported when home visits were made.



Details of how to get hold of this booklet are given at the end of this publication

What helpful things can be learnt from these families' experiences?

- Ask your professionals about options for deaf children that are not available locally.
- Go through the options discussed in the Early Support Information for parents booklet on *Deafness* and find out whether, and how, these booklets are provided in your area.
- If an option is not available in your area, ask your professionals to explain why this is the case.
- If your preferred option is not available in your area, ask for support to see if it can be made available.
- Consider compromise solutions that you'd be happy with and which could be provided.
- Ask for an independent advocate if you think it would help you.
- Ask professionals you work with to explain how the local authority or health authority is structured, so that you know who to meet or talk with in order to pursue the choice you want.
- Consider meeting with other parents who want a similar service and making a case for it to be introduced in your area.
- Contact The National Deaf Children's Society freephone helpline to find out what's happening elsewhere in the country or look at their website.
- If you feel a situation can't be resolved, think about other routes of action.

Find out how to contact NDCS at the back of the booklet

It's available, but can I use it?

Even when particular services or support are available in your area, it still may be difficult for you and your family to use them – for example, if you live a long way away from the service you'd like and have no transport to get there. Or maybe you have older children in school and this means certain appointment times are more difficult to get to. Practical barriers such as these can stop families making informed choices. It's important for professionals to think about how they can help to remove these barriers.

A meeting with a consultant has been arranged for the Sharma family. The meeting is to discuss whether Sandeep, a two-year-old twin, might be referred for a cochlear implant. The family have their own transport, so getting to the hospital is not a problem and both mum and dad work flexible hours, which means they can be free any time of day. However, the main challenge for the family is childcare. Sandeep and his twin brother do not attend a nursery and so on the day of the hospital appointment, their only option is to take both the boys with them. Because there is no crèche facility at the hospital, Sandeep's parents are worried that the children will distract them throughout the consultation and they won't be able to concentrate on what the consultant is saying. The family arrive early and explain the situation to the clinic manager. She provides another member of staff to play quietly with Sandeep and Sanjeev in the corner of the room, while the consultation takes place.

You may feel, like the Sharma family, that there are things that seem to get in the way and prevent you being able to make the best use of the opportunities you have. Or perhaps there are more pressing worries, like work, housing, paying bills or other issues for you that you need to sort out before you can really think about choices for your deaf child. Although a professional's role is to provide information and support about deafness, they may also be able to help or recommend someone who can help you to sort out these other concerns.



What helpful things can be learnt from the Sharma family's story?

- Think about what's stopping you making best use of all the opportunities that are available and discuss these barriers with the professionals who work with you.
- Share other worries with the professionals you meet. Ask if they're able to suggest any support in resolving them, or suggest someone else who could.

Would learning a new skill help me to make choices for my child?

Learning new skills and techniques can help families make choices for their deaf children. For example, when parents learn the best way to look after a child's hearing aids, they no longer have the stress of frequent visits to the clinic to get minor repairs or adjustments sorted out. Another example is that learning to express opinions more confidently in large meetings may help you play a bigger part in decision-making processes.

Parents and carers are meeting together at a regular monthly coffee morning for families with pre-school deaf children. The children are being supervised and playing happily in the playroom so the parents have an opportunity to talk with each other, the teacher of the deaf and specialist social worker with deaf children. As they chat, they realise that all of them would appreciate support in learning new skills. Jo and Alex, who are learning sign language, explain that they'd like to go to a sign class where the vocabulary was more appropriate for their two year old. Dave is finding all the visits to the audiology clinic very difficult to manage, especially as he cares for his child alone, and thinks it would be helpful if he could learn to make his baby's earmoulds himself. Yasmin says that she'd feel a lot more in control if she could lead some of the meetings about her son, as then things would go at a pace suitable for her mother, who uses an interpreter. Hedio thinks that her greatest need is to learn how to write formal letters as she feels that service managers and strategic planners of services would take more notice of her requests and suggestions if she

could do this. Sarah does not feel confident about representing her daughter who has a very complex range of disabilities. Mike says that he feels helpless because all the information seems to be on the internet and he has never learned how to use a computer. The whole group has ideas and suggestions.

The teacher of the deaf promises to get information about the new NDCS family sign language curriculum for Jo and Alex. In the meantime Hedio, who is Deaf herself, promises to help them with appropriate vocabulary. The social worker offers to support Dave by asking the audiology department about teaching parents to make earmoulds, as she knows that other parents in other areas have done this. Jo, who teaches computing skills, offers to help Mike overcome his fear of computers. Mike says he knows an advocacy service that sounds just right for Sarah and may also be able to help Hedio. The social worker agrees to look for funding and, if necessary childcare to enable them to use this service. The teacher of the deaf also suggests that an assertiveness class might help Sarah feel more confident. She says she knows that there is a half-day course for professionals on effective meetings and will look into the possibility of parents having this course run for them or for parents to be able to attend the same event as the professionals.

What can be learned from the experiences of these parents and carers?

- To achieve some choices you and your family may have to learn new skills.
- Consider whether there any practical skills that you could learn that would benefit you, your child or your family.
- Ask to be informed about any training sessions that are on offer and that are open to parents.
- Volunteer to take part in professional training by sharing your experiences as a parent.



Section three

What to expect from services and professionals who offer an Informed Choice approach

You can expect them to:

- tell you about all the options that might be possible for you and your deaf child, not just the ones that are available in the area where you live or the ones that professionals have personal experience of
- respect your values, beliefs and priorities in discussions and decision-making
- have up-to-date knowledge that is evidence based
- discuss options with you in terms of risks, benefits and uncertainties. It is not always easy to predict the consequences of some choices – much depends on the individuality of your child and family
- offer information which will not be biased or judgemental but is clear and comprehensive
- be flexible in how they make information available to you – not all families like to have information in the same way
- support you to increase your experience and understanding to help you make choices. This is an ongoing process
- have detailed knowledge and understanding of what an Informed Choice approach means in both theory and practice
- not pressurise you into making decisions, but give you time to consider all the options available
- encourage you to see that choices may change over time as the strengths and needs of your child become clearer and you grow in your own understanding and experience

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- be honest, open and transparent about what they can provide and what it may be more difficult for you to be able to access
- consider how barriers might be overcome where some choices are less available than others, and be prepared to work towards this
- try to see things from your point of view
- focus not only on your deaf child's needs but have a good understanding of your whole family's needs, strengths and priorities. Sometimes there might be other concerns for the family which make it difficult to focus on the particular needs of your deaf child
- help you grow in confidence about making choices and feel that decisions are being made in ways that are comfortable for your family and best for your child
- share their expertise about deafness with you in a way that respects your expertise about your own child and family situation
- not make assumptions as to what choices you will make and therefore fail to tell you about particular options
- support you in thinking through new and original ways of resolving your particular dilemma – this may be through contact with other parents and the support, knowledge and experience they can provide
- help you to make choices by thinking about your child's rights and respecting these, not just your own rights as parents in making choices.



Key questions to ask

1. Have I been told about all the options, not just those that are readily available in my area?
2. Have I been told about the pros and cons of all the options, not just the view of the professionals working with me and my child?
3. If some options are not available in my area, have my professionals been open and honest about the reasons for this and considered what we might do about it?
4. Have I been given the opportunity to talk to sources of independent advice and support?
5. What other support is available to help me fully understand the information and to discuss it and make choices for my family?

How this material was produced

We asked groups of parents and professionals to meet together in three different areas in England. We encouraged parents to discuss what they felt professionals had offered them choices about, how they had been offered choices and what choices they would really like to be offered. We wanted to know what stopped them asking for services they might want. We asked them what had helped them to make the choices they were pleased with. We asked them what made it easier or more difficult for them to make choices. They told us many stories from their own experiences. These were helpful to us and helpful to other parents who were there. Professionals talked about similar topics from their point of view. They shared with us the difficulties they face in making sure families are offered a good range of different services. They told us about what they tried to do to make sure families knew they had choices and could change their minds. They helped us to understand the way they worked and the pressures they were under.

The information from the parent and professional days and the other written information helped us to identify the really important points about Informed Choice. From these we were able to write this booklet. After the parents had read it, we asked them what they thought and what ideas they had about making it better. We used their ideas to improve the booklet and to write this version.

As well as the booklet for parents, we also wrote one for professionals. The information is similar. The same topics are discussed, but it's written differently. It's aimed at what professionals might want to know, just as this booklet is aimed at what parents might want to know. You can have a look at the professional booklet as well if you want. It's available from Early Support, free of charge. You can get one by ringing 0845 602 2260 and using reference number ES46.



As well as this direct work with parents and professionals, the team carried out a meta-study of the concept of 'Informed Choice' drawn from a wide range of research literature outside the field of deafness. Insights from this review* helped the facilitators on the consultation days, as well as feeding directly into the issues discussed in [Section two](#) of this booklet.



The National Deaf Children's Society's (NDCS) vision is of a future without barriers for every deaf child. The NDCS works to achieve this by:

- offering clear, balanced information and support to families; advocating for deaf children, young people and their families
- providing opportunities for young deaf people to develop social skills, confidence and independence
- working with professionals and policy makers to ensure high quality services are available for all
- campaigning and lobbying on behalf of deaf children, young people and their families.

The NDCS services include:

- a freephone helpline offering support and information to families, professionals and young deaf people
- a wide range of publications for both families and professionals
- information and support on audiology issues, including glue ear
- training and consultancy for professionals
- education and technology advice and support
- family weekends, special events, training and activities for families.

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

Open Monday to Friday 10am to 5pm.

Switchboard: 020 7490 8656 (voice and text).

* This literature review is published separately as Young, A M, Carr, G, Hunt, R, McCracken, W, Skipp, A, Tattersall, H (in press, 2006) *Informed choice and deaf children: Underpinning concepts and enduring challenges* Journal of Deaf Studies and Deaf Education

The University of Manchester is the largest single-site university in the UK, and secured the title of 'Higher Education Institution of the Year' at the Times Higher Awards 2005. The quality, breadth and volume of its research activity is unparalleled in the UK as indicated in the results of the independent Research Assessment Exercise (RAE).



The School of Nursing, Midwifery and Social Work attracts considerable funding and publishes extensively in internationally renowned journals. It draws from a wide range of expertise including both qualitative and quantitative research methods, with many studies using a combination of these approaches.

The School of Psychological Sciences is a flourishing centre of research. The 'Audiology and Deafness Group' is the UK leader for applied research in audiology and deafness which has a significant impact upon service delivery in the UK and abroad.



Early Support

Early Support is the central government mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across England. It is developing at a time of significant change, as part of the restructuring of children's services in response to *Every Child Matters* and alongside new integrated assessment, information and inspection frameworks for children's services.

Early Support builds on good practice. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children.

To find out more about the Early Support programme, visit www.earlysupport.org.uk

If you would like a copy of the Early Support publications mentioned in this booklet, which are available free of charge, please ring 0845 602 2260 and ask for the following:

Informed choice, families and deaf children ref ES46

Companion material developed in parallel with this publication for professionals.

Information for parents booklet on *Deafness* ref ES11

General information for families with young deaf children.

Monitoring protocol for deaf babies and children ref ES29

Material to help families observe and understand their child's development.

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