



Informed Choice, Families and Deaf Children

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Early Support

Helping every child succeed

Informed choice, families and deaf children Professional handbook







Contents

About this publication	1
Section one: Introduction	3
What does Informed Choice mean?	3
Context	3
Section two: Underpinning issues	8
Summary	8
Information, knowledge and understanding	9
Availability	9
Access to availability	10
Parents vary in their ability to make informed choices	10
Informed Choice in families' terms	10
Does Informed Choice mean we offer the same to everyone?	11
Are all issues open to Informed Choice?	11
The effect of individual choice on the choices other people make	12
Parents as experts	12
Informed Choice is an active process	12
Equality of resourcing	13
Operational constraints	13
Resource strategy and philosophy	13
Training	14
Attitudes and values	14

Section three: Developing practice	15
Summary	15
Appointments	17
Audiology	21
Communication	27
Family-to-family support	32
Information	36
Multi-agency working	42
Service structure and organisation	46
Training	50
Transport	54
Section four: Principles	58
Key principles supporting Informed Choice	58
Principles into practice	60
Section five: Additional materials and resources	62
How these guidelines were produced	66



About this publication

This publication was produced for Early Support by The National Deaf Children's Society 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 decisions that families take about and on behalf of young deaf children.

Companion material for families with young deaf children has been developed in parallel with this publication. *Helping you choose: making informed choices for you and your child* explores relevant issues from the perspective of parents and carers and should be read alongside this material.

The material can be used in a number of different ways, as:

- literature to improve individual understanding of the issues involved
- stimulus for debate, as teams work towards a shared understanding of what Informed Choice for families means
- a training resource
- a guide for services wishing to develop their practice who are looking for practical suggestions for actions to take
- a structured way of considering the implications of Informed Choice in relation to specific practice issues
- encouragement to 'think outside of the box' on relevant issues
- support for discussions between strategic planners with responsibility for delivering services to families.

Section one sets out background issues in relation to deaf children and their families.

Section two explores the nature of Informed Choice through 15 underpinning issues. These are designed to expand professional thinking and provide a background to discussions about implementing an Informed Choice approach in any context.

Some readers may find it useful to use the underpinning principles identified in [Section two](#) as quality markers against which to evaluate current practice and plan for change.

[Section three](#) focuses on the practical implications of the underpinning issues to support moving towards an Informed Choice approach to service provision in specific areas relevant to deaf children and their families.

[Sections two](#) and [three](#) are intended to complement each other. They both provide practical help to those wishing to implement an approach that promotes Informed Choice.

[Section four](#) describes principles to which services aiming to provide Informed Choice for families would need to adhere.

[Section five](#) lists the main resources referred to throughout this publication.



Section one: Introduction

What does Informed Choice mean?

Informed Choice means that families can make knowledgeable decisions, which reflect their own culture, values and views. It is based on access to comprehensive, unbiased and evidence-based information, about the full range of options.

An approach to service provision that promotes Informed Choice is one in which:

- service providers adopt open and flexible policies that effectively endorse a range of possibilities
- services and professionals make no value judgements about one option over another and this stance is reflected in their strategic decision-making and resourcing
- families are supported to reach decisions in ways that are sensitive to their individual strengths, resources, needs and experience
- Informed Choice is not seen as a one-off decision but as an ongoing process.

Context

A focus on Informed Choice for families with deaf children has emerged out of three related factors:

- the reported experience of families with deaf children who are not always informed about all of the options available
- an emphasis on the empowerment of parents and the importance of family-centred services
- a wider political and policy climate that encourages Informed Choice.

In recent years, discussion about Informed Choice, in all areas of life, has been much to the fore. In the health and education sectors, particularly in early education, the question of how statutory and voluntary sectors can enable service users to make informed choices has been highlighted by a number of policy initiatives and strategic developments.

This emphasis has developed in the context of a much wider debate about service user and patient choice as a key principle underpinning policy and practice development. It is enshrined in key documents and highlighted in a number of Government initiatives such as a patient's right to determine in which hospital they will be treated.¹ The Department of Health paper *Choices in healthcare* states that:

'All of us – not just some among the affluent middle classes – want the opportunity to share in decisions about our health and healthcare.'

'We want the right information, at the right time, as well suited to our personal needs as possible.'

'Our health needs are personal, and we would like services to be shaped around our needs.'

Standard 4 of the *National Service Framework for children, young people and maternity services*² says:

'Parents and their children should be central to the process of decision-making about their care, and receive appropriate information to exercise choice. They need to be fully informed and provided with information about the nature of the illness, different interventions and treatment options available to them and relevant support groups and voluntary organisations that might help them. Information needs vary at different stages of the patient journey so the provision of information should continue throughout the child or young person's journey.'

¹ *Building on the best: Choice, responsiveness and equity in the NHS* (DH, 2003).
Choose and book: Patient's choice of hospital and booked appointment – policy framework (DH 2004)

² *National Service Framework for children, young people and maternity services* (DH 2004)
www.dh.gov.uk



This wider context is important because it underlines that discussion of Informed Choice in relation to services for deaf children cannot easily be dismissed and because it puts a discussion of parental choice in this area on a Rights footing.

Informed Choice is emphasised in recent guidance relating to additional support services for families with young children. For example, *Together from the Start*³ says:

'Providing information to families is a key function of service provision. Good information enables families to remain in control as they take decisions about what to do. Difficulty accessing relevant information is positively disempowering in a situation that is often already very stressful.'

In a similar way, guidance issued in 2003 relating specifically to the development of services for young deaf children⁴ states:

'Early intervention/support services are provided to early identified deaf children and their families to empower families to take positive action on behalf of their child by ensuring that they understand the effects of deafness and have access to unbiased, accurate and up-to-date information.'

The same guidance goes on to say that:

'Families must be at the heart of any decision-making process about their child and need accurate, accessible, up-to-date information to support their understanding of how to respond positively to deafness in their child and to decide what to do. Information is at the heart of service provision, whether deafness is the main factor impacting on a child's development or one of a number of factors that will have an effect.'

³ *Together from the Start – practical guidance for professionals working with disabled children (birth to third birthday) and their families* (DfES, DH 2003)

⁴ *Developing early intervention/support services for deaf children and their families* (DfES, RNID 2003)

Informed Choice has long been recognised as an important issue for families of deaf children. The National Deaf Children's Society (NDCS) has based its vision, values, support and campaigning over many years on this principle. The organisation has sought to support parents in making informed choices for their children and families by providing information and advocacy services in a field where professional opinion can be polarised, particularly in relation to communication methodology and educational provision.

However, direct work with families continues to highlight the fact that parents and carers do not always feel they have received the right information and support to make informed choices, and sometimes 'don't know what they don't know'. Strong differences of view can limit choice and create distress and confusion for families. Services sometimes fail to deliver Informed Choice in practice, while being completely committed to supporting it in principle.

This publication has been developed in response to requests from both parents and professionals for a clear statement of key aspects of Informed Choice. The primary objective of the project has been to produce practical guidance to help services improve their practice. This goal cannot be achieved without unpicking the considerable complexity that underpins basic concepts and without addressing the whole notion of how Informed Choice can be promoted – not just what it means.



Companion material for families with young deaf children has been developed in parallel with this publication. *Helping you choose: making informed choices for you and your child* explores relevant issues from the perspective of parents and carers and should be read alongside this publication. Using the companion material for families, with families, is an important way to improve general understanding of the issues involved and, at a practical level, to increase the opportunities parents and others have to exercise Informed Choice.

All of this material should be read in conjunction with other key Early Support documents relating to services for deaf children and their families – in particular the *Early Support Professional Guidance* and the *Early Support Information for parents* booklet on *Deafness*.⁵ Routine use of the information booklet with families is itself an important element of professional practice supporting families to make informed choices, because it provides full, unbiased and accessible information in a standard format.

⁵ See back cover for details of how to get hold of these publications, or visit www.earlysupport.org.uk

Section two: Underpinning issues

Summary

Fifteen fundamental issues that guide an Informed Choice approach to service provision for families with deaf children are identified in this section. They are presented from the perspective of professional service providers.

While from a conceptual point of view it is helpful to distinguish different facets of Informed Choice in this way, in real life many of the issues are connected with each other.

The issues are not intended to be specific to any particular service or professional context. The material is cross-cutting and as relevant for multi-professional groups as for single services and individuals. It is also not organised by familiar themes for deaf children and families like 'educational choices', 'audiology' or 'information provision'.

The issues identified were derived from research with professionals and parents and from analysis of relevant literature outside the field of childhood deafness.

The underpinning issues are:

Information, knowledge and understanding

Availability

Access to availability

Parents vary in their ability to make informed choices

Informed Choice in families' terms

Does Informed Choice mean we offer the same to everyone?

Are all issues open to Informed Choice?

The effect of individual choice on the choices other people make

Parents as experts

Informed Choice is an active process

Equality of resourcing

Read more about this in [How these guidelines were produced](#)



Operational constraints
Resources strategy and philosophy
Training
Attitudes and values

Information, knowledge and understanding

High quality information is a crucial component in supporting families to make informed choices about their deaf child. Information must be available, accessible, accurate, comprehensive, relevant and meaningful to those who use it. Information is helpful in building the knowledge that is needed to make choices, but the provision of information alone does not necessarily guarantee understanding. Parents may know about something in theory, but not yet have the experience to understand the implications, risks and benefits of any particular choice in their particular circumstances. Simply providing information does not necessarily mean that families are enabled to make informed choices for and about their deaf child. The key relationship is between understanding and choice, not simply between information and choice. How parents are supported to increase their understanding of any information provided is a crucial process supporting Informed Choice.

Availability

The aim of providing information and support to parents is to be comprehensive, outlining the full range of options on any particular issue (such as communication choices) while avoiding partiality or bias. Sometimes there is a difference between informing parents about all the possible options for their child, and the options that are actually available from services in their local area. This is a problem. In situations where a potential choice is not available, the issue of whether it should be available and how it can be made available, is a crucial one for services to confront and parents to question. The extent to which service providers are upfront and honest about the range of provision that is possible, in contrast to what is actually available, is also a crucial component in parents reaching informed choices about their deaf children.

Access to availability

A range of services and support may be available, but there may nonetheless be barriers to these actually being possible, realistic or suitable choices from a family's point of view. These barriers may have absolutely nothing to do with a child's deafness, but may be more a reflection of a family's economic or social circumstances. Matching cultural and linguistic preferences may mean that choices that are theoretically available are inaccessible to some families in practice. Services that are not organised flexibly to meet individual family circumstances may limit the range of options that are feasible for any given family. Supporting access to choice is as crucial to offering Informed Choice, as making options available in the first place.

Parents vary in their ability to make informed choices

One of the common experiences of parents of deaf children is the constant need to make choices in relation to their child. This is the same for parents of other children, but in the case of deaf children there are more decisions to make, many which involve considering a bewildering range of potential options. Not everyone is equally used to making decisions or being a 'chooser'. People vary in their confidence and skills in making choices – this often depends on past experiences and past opportunities to exercise choice. Other factors such as self-esteem also play a role. Knowing how to empower and support parents to be confident choosers is a key component of promoting Informed Choice.

Informed Choice in families' terms

Informed choices in relation to deaf children are not just made on the basis of high quality, relevant information. Families also make decisions based on their own values, beliefs, culture, priorities and interests. Understanding the risks, benefits and consequences of any particular option will be thought about in the context of a family's particular value and belief system, as well as their social circumstances. Professionals may feel that they have offered families Informed Choice, but parents may not



perceive it that way if the decision-making process does not reflect the family's 'way of doing things'.

Does Informed Choice mean we offer the same to everyone?

It is often assumed that the basis of Informed Choice is that everyone is offered the same set of choices, commonly with regard to communication approaches, audiological options, or educational placement. However, to think about Informed Choice only in terms of equality of what is offered, is to miss the significance of the lack of equality in how families may take up what is offered. Families' strengths and needs vary enormously and while many will feel well equipped to engage with informed decision-making processes, many others may feel, at least initially, ill-equipped to do so. Therefore, while Informed Choice may imply that everyone ultimately has the same opportunities, it should be recognised that the routes to Informed Choice require different approaches to enable families to take up those opportunities. However, when professionals make judgements about what families might need, and about how and when they might need it, they should be aware of the danger of taking on a gatekeeping role, which may impede rather than promote Informed Choice.

Are all issues open to Informed Choice?

In theory, Informed Choice may seem to be a desirable framework for the consideration of all issues. However, there may be some areas in which exercising Informed Choice raises more complex considerations or even ethical dilemmas involving risk and harm. There may be instances where the rights of the child are in conflict with the wishes and choices of parents. On another level, there may be cases where an expressed preference may be at odds with an assessed need. At all levels, parents and professionals need to reflect on and openly share their assumptions about what is and is not open to Informed Choice.

The effect of individual choice on the choices other people make

An Informed Choice framework is frequently criticised for seeming to promote too individual an approach to the right to choose; one that ignores the consequences that one person's decisions can have on others. In a context of limited resourcing or scarce skills, professionals may find themselves making decisions that respond to the bigger picture of overall needs for several children, rather than only to the preferences of an individual parent. On the other hand, a choice that one parent might make for a particular kind of support, perhaps previously unavailable in an area, may have positive consequences for many other parents to whom this now becomes more widely available. This tension between the individual as chooser and the wider social consequences of any particular choice may be hard to reconcile for parents and professionals. However, upholding the rights and responsibilities of individual parents within an Informed Choice framework is of prime importance.

Parents as experts

The recognition and valuing of parents' expertise about their own child is fundamental to all considerations of Informed Choice. However, this expertise is not something static, nor is it fully formed. It is something that grows with their experience of their child and with their experience of deafness. Working together to develop and promote parents' expertise is as important as simply acknowledging it. If parents, quite rightly, draw on their knowledge of their child when making informed choices, then that expertise is something to be nurtured.

Informed Choice is an active process

It is essential for professionals and services to see Informed Choice as taking place within an evolving framework of provision. Family situations change; children grow and develop; parents gain knowledge and understanding. All of these mean that choices may need to be reconsidered over time. Professionals should empower parents to choose, re-choose and change their minds where this is appropriate. Making a



choice at a particular time should not mean that parents give up their right to make other choices at other times.

Equality of resourcing

Equality of opportunity for every family is a central theme within an Informed Choice framework. Services need to ensure that every child and family has an equal chance to achieve potential. However, since child and family needs are different and individual, this implies a flexible response to the use of resources (physical, social economic, or human). Criteria-driven resource allocation (eg based on level of deafness) may result in a resource-led rather than a needs-led model that reduces the opportunity for families to exercise Informed Choice. Two families whose situation, on the surface, looks similar may need very different resources to help them be confident and achieve the same outcomes. Achieving equal opportunity may sometimes require unequal resource allocation.

Operational constraints

It may seem like a 'get-out clause' to suggest that 'operational constraints' can mean that certain information is not provided, some choices are not available, or some services are not accessible. However, poor resourcing, low staffing levels, lack of training and skills shortages are very real constraints on service providers. There is a shortage of qualified speech and language therapists (SLTs) nationally, some equipment is in short supply and no-one has an infinite budget. However it is important to consider what are real operational constraints and what may just appear to be so. How much could be overcome through, for example, changing ways of working, challenging old systems, or building creative partnerships?

Resource strategy and philosophy

A service's underlying philosophy and its strategic implementation may have a significant effect on a family's opportunity to make informed choices. Local education authority commitment to mainstream inclusion may, for example, lead to reduced resources to support other choices. A strategic commitment to one specific approach or philosophy may, by implication, give the message that other approaches are of lesser value. This issue is

wide-ranging in relation to Informed Choice and should not be seen only in terms of educational placement and communication methodology.

Training

Training underpins many of the key concepts associated with Informed Choice, eg the provision of high quality, relevant information; increasing professional abilities to promote the empowerment of parents as active choosers; improving access to what is available; resource allocation decision-making and so forth. It is, therefore, a factor (like attitudes and values) that oils the wheels of Informed Choice as a successful process for both parents and professionals. All those involved in service planning and delivery, from practitioner to operational and strategic managers have continuing professional development (CPD) needs in this area. These may be met in a variety of ways, including by parent-led initiatives.

Attitudes and values

These operate at all levels and permeate all other underpinning issues. Attitudes and values, whether of professionals or parents, are inextricably linked to the promotion and practice of Informed Choice. After all, Informed Choice is itself a statement of a very particular value base. Values, whether explicit or implicit, underpin how decisions are taken and how they are enacted at all levels of professional activity (strategic planning, operational activity and professional practice). Professionals need to be aware of and honest about their own beliefs and opinions and realise that these should not be presented in ways that influence the decisions parents make. Strategically, the allocation of resources to a particular option may give a message that one choice is better than another choice. The key point is that as attitudes and values translate into professional activity, they should serve to promote, rather than impede Informed Choice. From a parental perspective, the extent to which the values, beliefs and priorities of families are taken into consideration is an important component of decision-making processes. This consideration of attitudes and values is likely to include respect, appropriate challenge and reciprocal sharing of expertise between parents and professionals.



Section three: Developing practice

Summary

Some readers may find it helpful to use the underpinning principles identified in [Section two](#) as quality markers against which to evaluate current practice and plan for change.

This section explores the underpinning issues in a practical way in terms of how services can move towards Informed Choice. It should be read in conjunction with [Section two](#), which provides a more in-depth understanding of issues and challenges. The aim here is not to provide a model for ideal service provision, but to support services in considering how an approach that positively encourages Informed Choice can be implemented.

The nine topic areas presented in this section are those that were raised most frequently by parents and professionals. The topic areas covered are:

- Appointments
- Audiology
- Communication
- Family-to-family support
- Information
- Multi-agency working
- Service structure and organisation
- Training
- Transport

Just as with the underpinning issues, many of these topic areas overlap with one another.

The topic areas are presented in alphabetical order and may be considered as a whole or independently. While they may be of

Read more about this in [How these guidelines were produced](#)

relevance to particular services, they are intended for use in a multi-agency and multi-professional context.

Each topic area is introduced in the context of Informed Choice. The focus is specifically on what enables parents to make informed choices, although many topics also echo general principles of family friendly service provision.

Service providers have shared a range of practical ideas and initiatives which actively support the development of Informed Choice at strategic and practice levels which are presented here as examples associated with particular topics. These examples indicate the steps some services have taken to move their practice forward. They are indicative rather than exhaustive.

Their purpose is to show how potential barriers can be overcome. They do not relate specifically to any one underpinning issue, or one topic but aim to show how a number of these can be addressed by creative service provision. Their use in this document is to illustrate how some services are facilitating Informed Choice for families.

There are references throughout this section to a number of the most recent government initiatives and guidance documents including Early Support programme materials that you are likely to already be using to develop local practice – for example, the *Early Support Professional Guidance* and the *Early Support Service Audit Tool*. *Change for Children* and other documents associated with the *Every Child Matters* agenda are also key documents informing service development. Full references of where to find any resources referred to in this document are listed in [Section five](#).



Appointments

Appointments in the context of Informed Choice

It is rare in life to have unrestricted choice about where, when and how we receive a service we require. Is it therefore unrealistic to suggest that appointments for deaf children and their families should be subject, in some way, to Informed Choice? Informed Choice in this context is not just about flexibility of service delivery, but is also about the manner in which appointments are set up and carried through. Good information about the purpose of any given appointment enables parents to make decisions about priorities and the extent to which personal and practical compromises should be made to keep that appointment (or not). Joined up information systems help professionals identify opportunities for combining different appointments to reduce the burdens of travel, time off work, and disruption to children and families. Paying attention to the range of factors that might impede parents' participation at appointments supports more joint decision-making. Being responsive to parental preferences about the timing and location of appointments promotes a greater sense of partnership. In other words, focusing on issues about how appointments are set up and conducted helps to create conditions in which parents are able to exercise Informed Choice in relation to the purpose, content and process of appointments. Addressing the extent to which the system dictates the degree of flexibility possible to meet parental preferences and analysing possibilities for change within that system are also vital elements of ensuring better conditions for the exercise of Informed Choice.

Parents told us that:

- they would like some choice about where and when appointments are held and whether appointments can be combined, as having many appointments in different places caused difficulty for them
- flexible and more frequent opening times for drop-in sessions would give better access to services, support and information

- they wanted to know the purpose of any appointments and what to expect if they attend
- it is difficult to take in information and make choices when being distracted by children
- children with disabilities are often given multiple appointments that are not co-ordinated and where information does not appear to be shared
- they would like to access appointments in their preferred language, but to have a choice about whether or not to have a member of their family doing the translating
- it is helpful to have a choice about whether and when to take someone with them to an appointment
- they appreciated continuity in the professionals who dealt with them
- the same considerations apply to professional visits in the home.

Professionals told us that:

- flexibility in the structure of their working week improved choice for families
- contractual arrangements have to be agreed to offer tailor-made services
- responding flexibly to family choices needs to be looked at alongside work/life balance policies for staff
- co-ordination at strategic and operational levels is required for shared appointments to be offered to families
- having information about the challenges families faced regarding appointments helped them understand the positive impact of providing choice.



These are some practical examples from services that support Informed Choice for families:

Offering parents choice of appointment times – for example, one audiology service invited parents to select a preferred time that fitted in with their other commitments.

Providing information about the expected length of appointment, the content of appointment, which professionals would be there and why and reminding parents they could bring whoever they wanted with them to listen or take notes for them.

Making parents aware of the whole team, so that greater choice was provided about continuity of care. Photos and an information booklet about the team were provided so that parents were able to see their key professionals in the context of a wider service.

Providing a keyworker to help support parents in co-ordinating their own meetings to empower them to understand the system and take control of their own service.

Making arrangements for children to be supervised when parents are talking to professionals. This has been achieved through supervised play areas, the use of ancillary helpers within hospitals, play facilities that family members can utilise, social care support or provision of a crèche.

Regularly reviewing and improving access to services in partnership with parents of children with additional needs.

Hospital departments and clinics synchronising their appointment systems as far as possible, so that families make a minimum number of visits to hospitals/clinics. For example, when multiple appointments are required, these are offered for the same day.

Offering appointments at the child's educational placement or outside school hours, to ensure minimum disruption in schooling.

Fast-tracking appointments for children with complex healthcare needs who are prone to health crises.

Ensuring that children and young people who find it hard to wait, eg those with autistic spectrum disorder or with learning disabilities, do not have to wait unduly at out-patient clinics, general practice surgeries or child development centres. Where appropriate, providing double-booking times or first/last appointment times for children with additional needs.

Making facilities for giving personal care in privacy available in all locations in health, social care and education services that are used by families with a child with personal/healthcare needs.

Offering a 'block' of appointment times and inviting parents to confirm/select a suitable time for them from the available slots.

Giving parking 'passes' to parents attending clinics.

Ensuring full knowledge of the family's situation and child's details, for example, by reading their notes or asking to see their *Early Support Family file*, before meeting with the family.

Practical example

In response to parental feedback about difficulty in fitting in appointments around other family commitments, one service changed their system from one whereby specific times and dates for each appointment were sent to families, to one in which parents were offered blocks of times to choose an appointment time within. Families would contact the service to select the time of their choice. This is sometimes known as a Partial Booking System. The Kenyon family, with two children aged 2 and 6, welcomed this move but felt that it still did not give them choice to have their children seen together, since the under 3s clinic was on one day and the clinic for children of school age was on another. After discussion with the service it was agreed that the children could be seen within the same clinic session by allocating the last clinic 'slot' as a double, which then gave time for adjusting the clinical set up for the older child.



Where to find out more

Key background documents to this discussion are:

Every Child Matters: Common Assessment Framework

www.everychildmatters.gov.uk

Audiology

Audiology in the context of Informed Choice

Audiology is a gateway service that identifies hearing loss and provides information to parents and to a range of service providers. Parents are unlikely to have met audiology services before or to have a clear understanding of what such services offer. Audiology brings with it a range of specialist jargon that may confuse parents. Initially parents may feel too shocked to request explanations or elaboration of information and feel unable to make informed choices in an area where they have little previous experience or knowledge. Parents may automatically accept earmoulds and amplification initially, only later questioning the potential benefits and restrictions. Of necessity parents rely on audiologists as experts. At the same time, parents need to be aware of the limitations of a purely audiology-based approach and be given opportunities to gather a wide range of information and opinions.

Parents told us that:

- they welcome early identification but wish it to be handled in a family-sensitive way
- audiological information is most helpful when explained simply and clearly over a number of visits and backed up by further discussion with a teacher of the deaf at home
- they prefer audiologists to explain amplification options, management and potential benefits and challenges openly

- at the point of identification it is easier if news is shared in private with the option of having a family member and/or teacher of the deaf present
- appointments arranged to take their needs, such as time, location, interpreters or other appointments into account are most helpful
- health specialists being located in one setting made visits easier to organise
- they recognise earmould provision is important and welcome choice relating to where, when and who takes earmould impressions as well as fast turnaround times for the moulds to be returned
- professional assumptions that categorised children into a specific group based on hearing loss alone are unhelpful.

Professionals told us that:

- it is sometimes difficult to balance issues about what is (or should be) parent choice as opposed to child choice (or in the best interests of the child)
- while willing to offer flexible service delivery – in the home, in the school, in the clinic – this has to be balanced against demands on staff time and other responsibilities
- they would welcome guidance to ensure national consistency about which children are offered hearing aids – children with mild and moderate losses are fitted in some areas but not in others
- they would appreciate an agreed pathway for audiology, detailing what information is given out, when and by whom, so that conflicting information is not given and staff co-ordinate their activity and utilise their strengths appropriately
- there is some professional territoriality around who should share the news of a child's hearing loss and discuss options with the family



- a lack of knowledge and research has led to uncertainty about what to do with 'new groups' of deaf children, such as those with auditory neuropathy and auditory processing difficulties
- contracts with certain other health providers limit parental choice – for example, when all cochlear implant referrals from a region are sent to a single cochlear implant centre
- having more staff available to carry out specialist investigations such as aetiological investigations and genetics testing would lead to greater equality of service provision to families
- limited resources for cochlear implant assessments and other provision leads to choice being taken away from parents.

These are some practical examples from services that support Informed Choice for families:

Training provided for all staff in deaf awareness, specifically relating to issues for deaf children.

Staff attending the *Empowering parents through Effective Communication* training run by the Medical Research Council and NDCS.

Offering appointments at the most appropriate time for families, especially if there are school age children in the family.

Offering the option of bringing a partner, relative or friend to appointments.

Providing information about play facilities near the clinical setting and about whether or not this is staffed.

Offering privacy when confidential and sensitive information is being discussed with adequate time for questions.

Sharing all the known facts with parents in a clear and honest way, including both what is known, what is not yet known and why that is the case.

If an appointment might confirm deafness, ensuring someone with counselling skills, usually a teacher of the deaf, is available on site. (A working space is provided so that the teacher can carry on with other work but be available quickly if the parents feel it would be helpful.)

Where English is not the language of the home, making appointment letters available in other major community languages and arranging interpreting services as necessary.

Providing parents with a hearing aid care kit including a forced air blower, attenuated stetoclip, battery tester and spare batteries, pre-bent tubing and a threader and appropriate training.

In addition to the care kit, the teacher of the deaf explaining daily management, with instructions available in written and or video/ CD-ROM format for parents, giving a range of NDCS materials together with management guides by manufacturers, the Ear Foundation and the Ewing Foundation.

Providing opportunities for both parents to ask questions and get detailed answers that are accessible regarding their child's audiogram, hearing aid management and troubleshooting.

Fast-tracking requests for paediatric earmoulds to help ensure consistency of amplification.

Dealing professionally with requests for reviews and support, with parent concerns being given appropriate attention. Keeping a log of all enquiries and requests from parents, teachers of the deaf, speech and language therapists and social care workers and reviewing amplification regularly to identify areas requiring action.

Automatically providing families with spares to ensure that children receive consistency of amplification.

Giving parents the option of seeing the ear, nose and throat (ENT) consultant biennially or when necessary, by request.

Explaining and discussing FM systems, auditory training units (ATUs) and other listening aids with parents and making them available when



appropriate. Also making parents aware of the Blue Peter NDCS loan system.

Discussing cochlear implant candidacy with the parents and providing the opportunity to meet other parents of implanted children and those who did not opt for implantation. Ensuring information is clear and accessible without any sense of coercion or pressure to make a choice immediately.

Making information available in a range of formats and appropriate community languages that clearly explains the criteria for implantation, funding streams and budgetary considerations, family responsibilities relating to implantation and long-term implications.

Practical example

Parents often express frustration about problems with earmoulds, and feel that the constant need for new earmould impressions, especially in the early months following confirmation of deafness impacts negatively on their experience of enjoying their child and getting on with their lives. In order to give parents more choice about managing this demand, one service set up a flexible system for earmould provision. This has involved the audiology and education support services working closely together, alongside parents.

Teachers of the deaf who regularly and routinely visit families have been trained and accredited by health services staff in earmould impression taking. The necessary insurance procedures have been dealt with by the health authority, and now parents can choose whether to have earmoulds made at the hospital or at home, or when visiting the education service base for other activities. Earmoulds can be delivered directly to parents' homes, or be collected, depending on parental wishes. Some parents have themselves been trained to take earmould impressions and now also have this option.

Excellent communication and flexibility in delivery and fitting have resulted in a system which supports real choice for families.

Where to find out more

Key background documents to this discussion are:

Early Support Service Audit Tool Standards: B1

www.earlysupport.org.uk

National Service Framework – *Standards for hospital services*

www.dh.gov.uk

MCHAS Guidelines:

Fitting, verification and evaluation of DSP hearing aids

www.psych-sci.manchester.ac.uk/mchas

Taking of impressions and provision of earmoulds

www.psych-sci.manchester.ac.uk/mchas

NHSP *Patient Journey* protocol

www.psych-sci.manchester.ac.uk/mchas

Do once and share

www.mrhear.info

NDCS *Quality Standards in Paediatric Audiology*

www.ndcs.org.uk



Communication

Communication in the context of Informed Choice

In many respects, the topic of communication choices is the most familiar when thinking about Informed Choice in relation to young deaf children. Failure to make parents aware of the full range of communication approaches available and failure to offer, support and resource all possible options, are common complaints. However, communication in the context of Informed Choice means more than being transparent about and providing access to all that might be available. It also means focusing on the processes by which parents become familiar with, explore and make judgements about different approaches to communication within the unique context of their child and their family. Choices are not made purely on the basis of information. They are also made on the basis of experience and with reference to an individual's own values, beliefs, priorities, aspirations and previous life experiences. Making informed choices about communication requires that parents make sense for themselves of the implications, expectations, advantages, risks and benefits of all the approaches to communication that are potentially available to their child. This may mean that parents and professionals engage in an iterative process whereby choices are not made as once and for all decisions. Communication choices reflect an evolving experience underpinned by high quality information and increasing knowledge and understanding.

Parents told us that:

- choosing their child's communication approach is one of the most important decisions they have to make
- deciding which mode of communication is right is often seen as a 'big one-off decision' that will be difficult to change in the future
- they want information about all types of communication and to understand the implications of different methods for their child and family
- choice is often limited by the provision that is available in the area in which they live

- they believe decisions about communication should be based on a child's needs and not on what services are provided locally
- they value being able to discuss communication openly with professionals, and that this is more difficult when professionals express a personal preference for a particular communication approach
- sometimes they find information about other communication options 'late'. Had they had this information earlier, they might have made a different choice or changed their choice as their child's needs changed.

Professionals told us that:

- deciding which communication approach a child will use is a major responsibility for parents and that the role of the professional is to inform and support parents through this process
- a range of expertise regarding communication options is needed within services in order to meet the needs of a range of children
- in some circumstances they found it difficult to offer a range of communication options due to practical constraints such as funding, professional expertise and small numbers of deaf children
- training and ongoing professional development are essential for updating knowledge and skills regarding communication options.

These are some practical examples from services that support Informed Choice for families:

Encourage parents to meet a range of families who have made different communication choices.

Providing access to a range of professionals who can explain specific communication choices, the implications of specific choices and the evidence base relating to outcomes.

Supporting families in reviewing their choices and making available resources that support change, if desired.

Providing independent publications that explain and discuss different communication choices.



Providing opportunities for staff to develop or further develop their communication skills to an appropriately high level.

Making reciprocal arrangements with neighbouring local authorities to share professional skills and input to families across boundaries.

A number of authorities jointly employing a teacher of the deaf with specialist skills to support families wanting a particular approach across a wider geographical area.

Providing a range of equipment and resources to support families in their communication choices, eg signing videos, story bags, auditory training units.

Making plans with the family that are reviewed regularly, about their choices and the child's needs so that appropriate educational provision can be made available.

Ensuring communication choices made by parents are supported by professionals who have skills and training in this area.

Seeking advice from other areas that have developed specific approaches and using this to develop alternative provision.

Practical example 1

Leanne's moderate bi-lateral sensori-neural hearing loss was confirmed when she was 10 weeks old. She was fitted with hearing aids almost immediately. She took well to the hearing aids and the family were keen to ensure her optimum communication development. Leanne's aided thresholds are around 45dB. In early discussions with the audiologist and the teacher of the deaf, Leanne's parents expressed a wish for her to follow a sign bilingual approach. Despite a professional feeling that a purely oral-aural approach would be a more natural choice, the service respected the family's wishes and arranged for appropriate high quality support to be given. On a routine weekly visit, Leanne's mum commented to the teacher of the deaf that Leanne was vocalising well and clearly using audition and that signs 'seemed to be getting in the way'. The teacher of the deaf responded by saying that perhaps Leanne was now showing a preference for oral communication and that the family might try using less sign and more spoken language. They agreed that, as usual, Leanne's progress would continue to be closely monitored but the teacher of the deaf would now adopt a more oral-aural approach and together they would revisit and review their decision in a few months time.



Practical example 2

A metropolitan borough had a long history of oral provision, and a staff trained to be strong in that particular approach. Children who had not 'thrived' with the approach, because there was no sign-bilingual provision within the service, went to a residential school for the deaf over 40 miles away – often at a young age. Consultation with parents showed overwhelming support for the development of signing provision within local mainstream schools. A decision was taken to develop sign bilingual provision, firstly at pre-school and in the primary phase, to parallel the high quality oral approach that was already in place. A number of steps were taken over a two-year period:

- The local authority undertook a cost-benefit analysis and developed a long-term strategic plan with an associated budget.
- Deaf staff were appointed to the service as teachers and support staff
- Discussions were initiated with a local primary school, with a nursery class attached, to be a host school. The admission policy of the school was modified so that sign-bilingual children were treated as a priority regardless of where they lived in the borough.
- Sign language classes were offered to parents, during the daytime and evening.
- All staff undertook training in issues relating to sign bilingualism.
- Service documentation and information was revised to support the offering of choice.
- Training was given to local authority officials and strategic managers and to colleagues in health, audiology and social services about the rationale for the development and changes to the way services operated.
- A series of meetings were held with parents, colleagues in mainstream and other support services.

Where to find out more

Key background document to this discussion is:

Communication options in the education of deaf children (Lynas, 1994)

A list of relevant and useful sites relating to communication options can be found in the *Early Support Information for parents* booklet on *Deafness*

www.earlysupport.org.uk

Family-to-family support

Family support in the context of Informed Choice

It is not just information, but also experience that is crucial in making informed choices. Through first-hand experience, theoretically available choices may come to be seen as real possibilities for the first time; instinctive preferences might be confirmed; or beliefs about what is right might be challenged. In this sense opportunities for family-to-family contact and support are vital. They add context (both in the immediate and long term) to the realities and consequences of having made particular choices as a family. They are a source of knowledge and understanding that is of a totally different variety than that available from the printed word, or through the explanations of professionals. Opportunities for family-to-family contact hold a mirror up to the choices that families might be contemplating. They give them the opportunity to see the ways in which both their children and family are just like the ones they are meeting, as well as not like those they meet. Such recognition of both similarities and differences, the opportunities for seeing the future through the eyes of other families, their practical and emotional support, and the lived wisdom of other families are vital resources in making decisions. They promote understanding of the risks and benefits of those decisions on families' terms.



Parents told us that:

- being with other parents of deaf children is very important in terms of sharing time with others who have been in the same situation
- group meetings (whether 'parent and toddler' or local deaf children's societies, etc) offer an invaluable source of support and information in a relaxed environment
- there is different value in having parent-to-parent support as opposed to professional to parent support
- they are interested in finding new ways of sharing ideas and information with other families, eg video conferencing
- they value meeting a range of d/Deaf adults and young people using different communication modes, with differing degrees of hearing loss and who had made different 'choices' in life.

Professionals told us that:

- 'paired parents' or 'mentor families' offer similar support to group meetings but on a smaller scale, and so may be more suitable than group support for some parents
- there is value in parents meeting families with older deaf children whose families have made different choices
- parent groups are a good way to give out information and meet with parents in a more neutral environment
- family-to-family support can give parents more confidence and self-belief
- it is important to give families the option to attend parent support groups but to appreciate that some families will not want to take up this offer
- setting up parent networks (for example, by giving out lists of other families' contact details) allows families to get the level of support they want.

These are some practical examples from services that support Informed Choice for families:

Giving out information about local groups.

Accessing the NDCS Family Supporter Network, where families (parents and grandparents) can be put in touch with other similar families .

Providing information about Contact a Family – especially helpful for families of deaf children with complex needs or disabilities.

www.cafamily.org.uk

Promoting a parent-to-parent network locally – providing a venue and some support resources for parents to meet and organise self-help activities.

Being sensitive to cultural need, providing an environment which is suitable and accessible for parents who might find themselves excluded in a general meeting.

Putting parents in contact with other mainstream parenting and parent-to-parent initiatives, through Sure Start, Portage etc.

Telling parents about Parent Place, a part of the NDCS website offering a parent-to-parent email forum.

Arranging a telephone contact network for local parents.

Setting up a local Parent-Teacher Association.

Inviting parent representatives to set up a parent support group to run parallel with an audiology clinic, and providing a room to do this.

Giving parents information about NDCS family days and residential weekends.

Helping parents to produce their own 'Parent-to-Parent' information resource and including it when giving out Early Support and Service information.

Providing Service Information evenings with a social element to facilitate contact.



Practical example

One service in a unitary authority and with a small and diverse population of deaf children and families found it difficult to facilitate family-to-family support. They took the opportunity to engage with the NDCS services to achieve this aim.

The NDCS has set up two initiatives which can support services in ensuring that family-to-family support is made available, to supplement local arrangements, and a number of services have chosen to give details of these to all families.

The first is the Family Support Network, a national scheme which enables families to meet and be in touch with, and offer support to families similar to their own. The scheme also provides training to parents and opportunities to get together in larger groups as well as individually.

The second is a web-based resource called Parent Place, part of the NDCS website, where parents can ask questions and receive answers from other parents on a whole variety of topics, or just exchange experiences and views.

The NDCS also offers a network of family weekends for parents and siblings of newly diagnosed children, and a number of Family Information and Activity days across the UK.

Where to find out more

Key background documents to this discussion are:

Early Support Service Audit Tool Standards: A6, B5
www.earlysupport.org.uk

Early Support Professional Guidance – Section 9
www.earlysupport.org.uk

Every Child Matters: Working with voluntary and community organisations to deliver change for children and young people
www.everychildmatters.gov.uk

www.ndcs.org.uk

Information

Information in the context of Informed Choice

The nature, purpose, provision and use of information are fundamental considerations in the practice of Informed Choice. Although information alone does not facilitate choice, without information it is largely impossible to weigh up alternatives, be aware of options, or even simply engage with the processes involved in making decisions. For information to be effective within the context of Informed Choice, it has to be up to date, unbiased, evidence based, relevant, and meaningful. Information that addresses the risks and benefits of particular courses of action, as well as highlighting uncertainties is known to be helpful. However, information cannot fulfil any of its key functions if it is not accessible to those for whom it is intended.

A focus on accessibility draws attention on the one hand to issues of language and format. On the other hand, it also raises issues about how information is made available and whether the very processes involved in accessing information create barriers to the promotion of Informed Choice. Information is just one element promoting the knowledge and understanding that enables parents to make choices.



Parents told us that:

- having too much information is better than not enough and the earlier this is shared the better. 'The sooner you start informing yourself, the sooner you can start doing something about it.'
- parent-to-parent groups are good places to share information
- they want information early and to have 'the system' explained. From the earliest point they want to know about the processes they will be involved in and the roles of different professionals
- information needs to be available in a range of language and formats
- they like having information to take away with them so that they can take it home to consider and pass on details to other members of their family with whom they are sharing the decision-making
- they want information about services that are available regionally and nationally as well as in their local area
- sometimes they only find out things when they meet parents from other areas. Lack of transparency or full information makes parents ask what else they don't know about
- they need time and support to take in information. This includes tailoring information to be relevant for the family, for example, having particular choices explained in terms of what they would mean for their child and family
- when information is not shared with families they are unsure if this is because professionals are 'gatekeeping' information or because they simply do not know.

Professionals told us that:

- providing information to support Informed Choice is as much a question of 'when' as 'what'
- 'at the time of identification parents come away confused, indicating lack of clarity in how information is conveyed'
- it can be difficult to give out full information about options when aware that some are not supported in the local area or the team does not have the skills needed to deliver them
- it is important to acknowledge what is within their remit to give information about, and be able to signpost families on to other services
- high quality, nationally produced and evaluated materials support Informed Choice as they contain consistent and standard information for all families
- information should include information about social care options that may not appear immediately relevant to the practitioner – for example, the possibility of respite care or a babysitting service being available.

These are some practical examples from services that support Informed Choice for families:

Handing out contact details for NDCS at the point of identification of deafness and encouraging families to make contact to get independent information.

When giving information about choices, making sure it covers the implications of the choice for the child and family – both in the short and medium term – for example, choosing a certain communication approach brings with it the need to learn new skills and commitment.

Regularly checking that parents feel confident in understanding the information you have given them, reviewing and updating it.

Making sure that all families receive the Early Support materials and ensuring a professional makes time to discuss the materials with individual families.



Holding multi-agency meetings in which you agree the care pathway and information provision 'trigger points' for deaf children, ie what information they receive, when and from whom.

Ensuring that all of the information produced locally is developed in consultation with families. Finding out from them what information is needed as well as asking their opinions on format, accessibility etc.

Services sharing translations of materials with other agencies to keep down costs and make them more widely available.

Inviting speakers from a range of organisations to come to the regular parent meetings or local deaf children's society (DCS) group meetings and give information about what they do. Examples include Delta, British Deaf Association (BDA), schools for the deaf and local speech and language therapy representatives.

Organising a 'family information day' or asking an agency from outside the area to facilitate a family event. These could provide specific information (eg for families of newly diagnosed deaf children) as well as facilitating the exchange of information between families.

When planning opportunities for sharing information with families, making sure venues and ways of delivery are accessible for all service users.

Practical example

A service which supports a multicultural population has organised highly specialised carer and toddler groups. Many of the mothers of the deaf children on the service's caseloads are from Asian communities and have particular cultural needs.

The service has taken steps to make these groups as accessible as possible to mothers and uses them as a method of sharing information.

- Taxis are provided to collect mothers and their children from home to take them to the resource base. Funding for this is provided by social services.
- The groups are for women only.
- Trained Asian support workers are employed to act as interpreters and to explain issues in a culturally sensitive way. This is done in conjunction with the council's interpretation service.
- In recent sessions, they have focused on parts of the *Early Support Information for parents* booklet on *Deafness*, translating it and encouraging mums to ask questions in their preferred language.



Where to find out more

Key background documents to this discussion are:

Early Support Service Audit Tool – Section 7 – Providing and Sharing Information, Standards: D1 – D4

www.earlysupport.org.uk

Early Support Service Audit Tool Standards: B3, C3

www.earlysupport.org.uk

Early Support Professional Guidance, Section 5

www.earlysupport.org.uk

National Service Framework for children, young people and maternity services

www.dh.gov.uk

Every Child Matters: Information sharing

www.everychildmatters.gov.uk

User-friendly information for families with disabled children: a guide to good practice (Mitchell & Sloper, 2000)

Early Support Information for parents booklet on Deafness

www.earlysupport.org.uk

Multi-agency working

Multi-agency working in the context of Informed Choice

When services do not just co-exist but work in a deliberately co-ordinated fashion, it is often possible to offer families much more than the sum of the parts of each service. Pooled budgets, joint strategic planning, flexibility in the roles played by individual professionals, and a strong ethos of co-ordination around the individual needs and strengths of families all contribute to a more comprehensive service. This kind of holistic approach is also good for identifying and working to overcome barriers to the exercising of Informed Choice. Multi-agency working can be comprehensive in tackling such barriers as these, as well as comprehensive in the enhanced range of available support and resources that together could be provided.

Parents told us that:

- co-ordinated service delivery where professionals clearly collaborate provides a sense of cohesion and support for families, which empowers them to make informed choices
- an assigned person with professional status coordinating
 - i) the information professionals had about the child and family,
 - ii) the frequency and timings of appointments, is particularly helpful.Those who had keyworkers were very pleased with the role they played
- multi-professional meetings and joint appointments promote a sense of effective and supportive team working
- they value the opportunity to be part of the multi-agency team as an equal member
- all members of the multidisciplinary team involved in their child's care contributing to any assessments or reports written about their child helps to ensure a rounded picture was achieved
- a good quality, integrated, well co-ordinated service is more important than who performs any particular task



- it is particularly helpful when there is a keyworker who understands the system
- professionals who can adapt to the changing needs of families provide a sense of responsiveness and tailored support that is valued
- an explanation of professional systems and how they work is useful
- it is important to know to whom to address comments and complaints
- there is a shortage of specialised trained professionals who can assess or provide direct services to meet their deaf child's needs.

Professionals told us that:

- multi-agency teams work best where there is understanding and respect for each member's role and professional boundaries
- multi-agency working is underpinned by joint training, planning and protocols
- co-terminous geographical boundaries help with multidisciplinary team planning.

These are some practical examples from services that support Informed Choice for families:

Using pooled budgets to run multi-agency training days to promote a sense of joint working and to provide a clearer understanding of roles and responsibilities which helps to make parents more knowledgeable about services and their options.

Using the Common Assessment Framework (CAF) to promote co-ordinated service delivery with reported reduction of the number of assessments, efficient information sharing and faster interagency referrals.

Developing a directory of local and national services, in line with *Every Child Matters: Change for Children*, that includes all aspects of child health, social and educational care. (Clearly and simply explaining how systems of delivery work, parental and child rights and allowances and providing contact details.)

Establishing multi-agency Children's Hearing Services Working Groups (CHSWG) that involve a range of service providers and service users to provide an important forum for discussion.

Ensuring other expertise is drawn in appropriately, for example, an occupational therapist to access equipment that allows a child with a disability to sit in a way that facilitates sign language or lip reading.

Maximising the expertise social care workers have in supporting families through issues that from the families' perspectives are more urgent, for example housing issues and benefits.

Running family days involving a range of professionals, the NDCS and volunteers, allowing families to meet professionals out of role in a relaxed atmosphere. This is reported to increase parents' sense of being in the team and developing a sense of trust and empowerment.

Using an outside facilitator to aid development where challenges to multi-agency working are considerable and longstanding barriers need to be challenged.

Arranging joint visits by professionals thereby helping role release and fostering a sense of trust between professionals.

Providing 'maps' of how services are structured.

Providing good multi-professional training and opportunities to meet regularly.

Training a portage worker (who visits a family daily) to be competent in hearing aid management.

Providing a directory of services which is clear, accessible, up to date and user friendly.



Practical example 1

One multi-agency team has set up a contract with the local spoken language and sign language agency which sets out how they will guarantee payment for any interpreting or translation services required by a client. This prevents families being in the position of always having to ask a service to cover the costs of interpretation, particularly when the situation may be an awkward one of potential conflict. It also enables any member of a multi-agency team to arrange interpreters.

Practical example 2

Driven by an active Children's Hearing Services Working Group and the involvement of parents keen to ensure that support for deaf children and families is integrated at the point of delivery, a number of services have developed 'integrated care pathways' and multi-agency planning groups, involving key practitioners/managers from all services as well as parents who work as a team.

One such team has developed a single information booklet for families with clear explanations of the different functions of the professionals involved, photographs of the personnel, and the type of support they can offer. Parents are therefore aware of the fuller picture, enabling them to make active choices about the type and extent of input they need at various times, and who to discuss this with.

The booklet makes explicit not only the range of services and options available locally, but also gives the broader picture. Parents are also given an overview of the way services in the area are structured and managed, so they can discuss potential choices at a variety of levels. The information is kept electronically, updated regularly and as required, and printed off when needed, saving costly outgoings on publication and need for reprinting.

Where to find out more

Key background documents to this discussion are:

Every Child Matters: Multi-agency working toolkit
www.plainenglish.co.uk

Every Child Matters: Lead professional good practice guidance for children with additional needs
www.everychildmatters.gov.uk

Early Support Professional Guidance Section 7 and Section 9
www.earlysupport.org.uk

Early Support Service Audit Tool Standards: A5, B4, C5
www.earlysupport.org.uk

Service structure and organisation

Service structure and organisation in the context of Informed Choice

Much of the discussion about Informed Choice often happens at the level of parent/professional relationships. However, services are often unable to move towards ways of working that are consistent with Informed Choice, without considerable reform to the organisational structures and systems that underpin uni-professional and multi-professional service provision. For example, increased flexibility in appointment times, or the settings used for professional encounters might promote greater parental engagement on terms that make sense to them, but such flexibility is not easy to achieve. Contractual obligations, funding priorities and professional commitments might all get in the way. The key point is that for Informed Choice to work, then changes must also be made at a strategic level that address issues to do with the organisation and structure that underpin service delivery. Informed Choice has a place in professional decision-making at all levels and in the very culture of how organisations operate internally



Parents told us that:

- they want to know which services deaf children are routinely offered, and that have automatic access
- they prefer provision based in local centres, rather than all hospital-based so that parents can choose where meetings take place
- it is important that all generic practitioners they may deal with (eg physiotherapists, occupational therapists, etc who are not 'deaf specific') are aware of issues faced by deaf children and their families. They want staff they work closely with to be specialists, or have considerable experience, in deafness (eg speech and language therapists, social services, educational psychologists)
- cross-county or cross-authority co-ordination of services (in terms of out-of-county school placements, cochlear implant centres, children with additional needs) helps to actively facilitate Informed Choice
- the need for and relevance of social services involvement is poorly understood. Parents sometimes feel they have done something wrong if they are contacted by social services
- if they require support with equipment from social services there are frequently unacceptably long waits
- they often feel they get fuller information and better support from non-statutory services and do not understand why contact with these is not more actively encouraged by support services.

Professionals told us that:

- in many areas Heads of Sensory Service seeking to influence strategic decisions are too low down the pecking order to be influential. It is hard for them to ensure deaf children and families' needs are properly understood at a high enough level
- regional centres have specific benefits but these need to be weighed against access issues and redirection of funding
- the involvement of d/Deaf professionals within services at all levels helps to promote positive deaf awareness

- the lack of social care workers specifically trained in the field of childhood deafness is a major problem
- they are concerned about the tension between tailoring services to meet individual families' needs and offering a service of a consistent level
- lack of co-terminous boundaries causes difficulties with service organisation
- joint visits (eg from a teacher of the deaf and speech and language therapist) promote joint working but can also mean duplication and loss of focus and therefore co-ordination of skills is essential.

These are some practical examples from services that support Informed Choice for families:

Providing training for local education authority (LEA), special educational needs (SEN) officers/staff involved at a strategic level on disability specific issues.

Subscribing to websites (eg Children Now) and monitoring DfES/DH websites for news of new funding opportunities and initiatives.

Feeding information about service performance/needs/pressures upwards to keep senior staff and service planners up to date.

Auditing service performance and provision against nationally recommended quality standards and protocols.

To fulfil Health and Safety requirements some services have contracts to work with another 24-hour service (eg social services emergency duty team) for when making out-of-hours visits.

Collecting evidence of impact/cost-benefit of service delivery to support the case for service development.

Ensuring effective use of Children's Hearing Services Working Groups in making strategic partners to facilitate joint planning.

Ensuring that strategic level managers are aware of the sort of issues that need to be addressed at a strategic level in order to facilitate Informed Choice at practitioner and operational levels.



Regularly consulting service users to gather feedback on services delivered – and publishing and disseminating findings.

Including user groups in both service planning and evaluation.

Engaging community leaders to support the involvement of groups who do not currently utilise services.

Establishing links with 'universal' services – Parent Partnerships, Home Start, Sure Start, Early Years Childcare and Development Partnerships etc – to embed services in a wider framework which supports parents.

Practical example 1

One service, together with the audiological physician from the main hospital, has made arrangements with a local Children's Centre to offer integrated services to parents of deaf children from a single location. Although funded from their respective agencies, the professionals involved (audiological, teacher of the deaf, speech and language therapist, Parent Partnership representative, social worker, Deaf instructor) have created a team delivery in partnership with the core centre staff in order to ensure a holistic approach. Deaf children and their families have targeted input and services from the team, and also share the advantages of extensive Children's Centre provision. This supportive framework is offered not only to children in the immediate locality but also on a wider basis to deaf children under the care of the audiological physician who reside in educational authorities outside the host centre's area.

Practical example 2

In a metropolitan borough, arrangements were made contractually between education and health services to set up an integrated clinic and follow-up service for families. This has resulted in a three-way collaboration between the ENT service, the audiology service and the education service for deaf children to deliver co-ordinated services. Assessment clinics are held jointly. A teacher of the deaf trained in counselling skills is part of the assessment/diagnostic clinic set up. Between confirmation of loss and the first appointment for follow-up with ENT, the teacher of the deaf visits the family at home and is then present also at the ENT clinic. In this way the teacher of the deaf acts as a key family link throughout the diagnostic process, and takes the support forward into follow-up provision. Evaluation with families has been universally positive.

Where to find out more

Key background documents to this discussion are:

Early Support Service Audit Tool Standards: A1, B2
www.earlysupport.org.uk

Every Child Matters – Joint planning and commissioning framework for children, young people and maternity services
www.everychildmatters.gov.uk

Training

Training in the context of Informed Choice

From a professional perspective, training and the practice of Informed Choice go hand in hand. This is primarily because of the fundamental responsibility that all service providers have to remain up to date and evidence based in the information that they provide to parents – whether that be through personal interactions, written resources or in the structure and style of the service they provide. The topic of Informed Choice itself, what it means, and what it implies for practice may itself be identified as



a training need. There are crucial skills that can be learned or honed that will improve practice with families. Some of these are to do with parent/professional partnership and encompass such issues as promoting parent empowerment, holistic family assessment, responding to conflict, working in a family friendly way. Others are to do with strategic decision-making, including resource allocation and multi-agency working. In many respects these subjects are quite common and it could be argued, not really special to Informed Choice. However, it is difficult to move towards the practice of Informed Choice without an approach that deliberately places such training needs within the specific context of Informed Choice, not just the general context of developing good professional practice.

Parents told us that:

- a range of professionals with expertise and training in specific areas support parents' ability to make real choices. This is particularly true of issues relating to communication (eg teachers who can support British Sign Language)
- they welcome the opportunity to take part in training courses specifically aimed at parents as well as joint parent-professional courses
- they specifically want training in hearing aid management, making earmoulds and communication, particularly learning sign language
- it is important to have staff who understand their choices, can support them and are trained in a variety of ways so that there are no barriers to having choices made available.

Professionals told us that:

- they value the opportunity to take part in multi-agency training and learn alongside colleagues but this is frequently not available
- continuing professional development is important for updating knowledge and skills
- they would like training in areas such as multi-agency working, working with pre-school age children and how to put Informed Choice into practice

- there are practical difficulties in arranging training across agencies
- there are logistical issues around professional training that parents also attend such as: suitable times for parents may fall outside of professionals' routine working hours; who pays for travel and childcare; how are attendees selected where places are limited
- training opportunities for parents are limited and more could be improved and developed.

These are some practical examples from services that support Informed Choice for families:

Providing opportunities for parents to attend some training with professionals. This has the effect of enabling families to feel more embedded within services and more empowered in discussions about their own child and to have a greater understanding of demands on service providers.

Organising training across health, education and social services (in some cases being run internally or using an outside facilitator, eg from a voluntary organisation or professional body).

Organising training within a federation of services (eg early years support staff).

The initial training staff undertake should involve gaining experience of wider perspectives in the field.

Influencing professional and voluntary organisations to have relevant and sufficiently detailed training opportunities to support continuing professional development (eg NDCS/Institute of Hearing Research (IHR) training on *Empowering Parents through Effective Communication* and using the Deafness @ birth website www.deafnessatbirth.org.uk and the NHS Newborn Hearing Screening Programme website www.nhsp.info)



Taking advantage of training offered by specific groups on specialised subjects (Tay Sachs group training or Relate on developing counselling skills).

Taking advantage of opportunities for training within Higher Education (eg Master level training in early years).

Investigating the possibility of working with industry to develop new skill sets (eg manufacturer training in making earmould impressions).

Practical example

One service carrying out its annual audit of parental satisfaction noted that some parents were keen to access training opportunities. Parents particularly identified taking earmould impressions, understanding audiograms and assessing communication development as key areas they wanted to learn more about. The service organised a family day on a Saturday, providing a crèche and supervised activity for the children, allowing parents and close family members to access training and workshops on the areas they had identified as priorities. Parents were also invited to attend the professional training day on communication skills. The service also arranged sessions where parents learnt to take earmould impressions.

In one local authority joint training was organised through the Tay Sachs association who ran a training session for teachers, social workers and health professionals on counselling skills.

Where to find out more

Key background documents to this discussion are:

Early Support Service Audit Tool Standard: A4
www.earlysupport.org.uk

Every Child Matters – Common core of skills and knowledge for the children's workforce
www.everychildmatters.gov.uk

www.deafnessatbirth.org.uk

Transport

Transport in the context of Informed Choice

It is easy to assume that if we make a range of choices available to families then all families will have equal rights and equal opportunities to make informed choices. The problem is that often structural barriers exist for families that mean that they might rule out certain options simply because other concerns make a given option unrealistic. Transport is one such barrier and we include it here because it was so frequently mentioned by parents and professionals. Recognising and addressing problems associated with transport for families makes two things happen. Firstly, the range of available and accessible choices expands, opening up new support and resource possibilities for families. Secondly, services directly address a key problem in the provision of Informed Choice, namely that the playing field is not a level one for all families. The provision of choice alone does not level it; direct intervention to address other factors that impede or restrict uptake of available choice is also required.

Parents told us that:

- they value a choice of transport options being provided as it makes it easier to attend appointments, take up early years educational opportunities and to meet other families
- they want information about the full range of help that is available with transport
- sometimes their choice of service cannot be accessed because the transport options available to them are not suitable – for example when their choice of nursery means that their child would be in a taxi for an hour because of a set 'route' being followed with multiple pick-ups and drop-offs
- the provision of transport or reduced cost parking helps to make more choices available
- it is helpful to have information such as direct contact details for taxi firms and escorts, so that parents can contact transport providers direct.



Professionals told us that:

- they recognise that transport is an important issue for families and lack of support for transport restricts the choice of services families can access
- it could be difficult to provide transport for families as services had limited budgets and therefore they needed more knowledge of alternative funding sources and providers
- there are often specific criteria which have to be met by families wanting transport and this excludes many families who need to use the service
- it is important that drivers and escorts understand the needs of deaf children and can communicate with them.

These are some practical examples from services that support Informed Choice for families:

Providing full information about when and how families can access 'statutory' transport. Preparing a practical resource which sets out details of types of transport, pick-up points, support available, if transport can be arranged to alternative addresses such as for childcare after school etc. In other words, a provision of a 'guide to transport options for parents'.

Giving a named contact who can advise and support families with regards to their transport needs, what provision is available and what additional sources of support may be available such as 'blue badges', welfare benefits, free public transport passes.

Having a clear transport policy that sets out the circumstances in which it applies and the eligibility criteria for access, together with information about how to appeal.

Undertaking an audit of current transport provision, getting feedback from service users, and developing a plan to broaden access in order to maximise choice for families.

Regularly reviewing transport routes and times in order to match the distribution of children and their families, and the locations and services they have chosen to access.

Having quality assurance and performance criteria established to monitor the organisation and provision of transport for children and families.

Providing escorts, who have undertaken appropriate training and been subject to child protection procedures such as Criminal Records Bureau (CRB) checks, where children travel without a family member, eg to nursery.

Making arrangements for the joint provision and route planning across departments and services.

Developing flexible family friendly transport schemes such as parent and child parking, free parking or car sharing. Not scheduling meetings and appointments at peak travel times.

Ensuring that when tenders for transport contracts were received, they were granted to companies that providers understood could meet the children's and families' needs.



Practical example

One local authority undertook a review of its transport policy and provision. This included asking parents about:

- what they used the current service for
- what the advantages and limitations of the current service were
- what difficulties they had encountered when using the service
- how the service could be improved.

As a result, the authority extended the transport options available to families by:

- providing access to the 'dial-and-ride' scheme for help in going to appointments, meetings and groups
- the development of a volunteer transport network. Where volunteers who had undergone the relevant training and CRB checks, as well as having relevant insurance, provided a free transport service for families with deaf and disabled children
- paying parents an allowance if they transported their child to and from an educational placement, instead of using the local authority taxi scheme
- setting up a training scheme for taxi drivers and escorts in understanding the needs of children as well as communication strategies
- ensuring that no journey was an unacceptable length for a child (as judged by the parents).

Where to find out more

Key background document to this discussion is:

Home to school transport for children with special educational needs – good practice guidance, Teachernet
www.teachernet.gov.uk

Section four: Principles

Key principles supporting Informed Choice

- All services at all levels have a responsibility to address the issue of Informed Choice and to take action to ensure its implementation.
- All services and agencies should ensure that families receive full, evidence-based and impartial information in a form that is accessible to them. This information should be about all options, regardless of whether these are available locally.
- Eligibility criteria for access to services and provision should be fully explained and enacted flexibly to support true Informed Choice for parents.
- Families should be offered appropriate support to ensure they fully understand the information they receive. This might be in the form of appropriate interpretation, through a range of media which meets individual needs, or by the provision of a variety of first-hand experiences.
- The individual cultures, values and opinions of families and the effect of those on informed decision-making should be understood and respected by professionals.
- Providing access to a range of choices may necessitate addressing a range of other social and economic needs experienced by families.
- Services should ensure that all families receive the Early Support materials including *Helping you choose: Making informed choices for you and your child* and that professionals make time to discuss these materials with families to support their use.
- Services should have robust systems in place to support families of deaf children to meet other families and facilitate parent-to-parent support.
- Services should ensure that families receive information about The National Deaf Children's Society and any local voluntary groups, from the time of identification onwards.



- Services should recognise that Informed Choice is an active process and support families in evaluating, re-evaluating and revising choices when needed.
- Professionals should be honest and open with families about what they can and cannot provide and the reasons for this in a neutral, balanced fashion. Services should work to remove these restrictions rather than simply accept them. Clear policies, shared by all agencies, should be agreed at both strategic and operational levels.
- All agencies delivering services to deaf children and families should agree, and make available, a co-ordinated policy and practice statement on Informed Choice that addresses actions to maximise its provision.
- Service provision should not adopt any blanket policy which would serve to restrict opportunity for individual families to make choices based on their understanding of their own child's needs.
- Services should ensure that all professionals involved in supporting families' decision-making undertake multi-agency training in Informed Choice.
- Information delivery and service practice must be unbiased, equitable and non-judgemental and should not be influenced by the personal views or philosophy of individual service planners and deliverers.
- Services should ensure that the information they provide outlines the implications of any choices for the child and family, both in the immediate and longer term. Risks and benefits of choices should be presented without value judgement and families should be signposted to other information sources which can help give them a breadth of views on different issues.

Principles into practice

For Informed Choice to be available, there needs to be clear commitment to it at all levels. The following should therefore be put into place:

At a strategic level:

- A designated lead person with responsibility for encouraging Informed Choice with a multi-agency remit.
- An overarching policy on Informed Choice.
- Clear identification of targets and funding relating to the implementation of Informed Choice in strategic plans.
- Mechanisms for planned and regular consultation to gather feedback from service users.
- Clear arrangements for cross-boundary partnership, commissioning of resources and pooled budgets.
- An audit based on the above principles of Informed Choice.

At an operational/team level:

- A statement and policy about translating Informed Choice into service practice, identifying key milestones and timelines within operational plans.
- Regular, planned consultation and review with service users.
- Clear protocols for multi-agency working agreed and used by all agencies involved.
- A staffing complement which ensures the balanced skill mix needed to deliver Informed Choice.



At a practitioner level:

- Staff skilled in a variety of communication approaches and with in-depth knowledge about all amplification and support options.
- Training so that all practitioners have an understanding of, and commitment to Informed Choice, and are skilled in giving information and supporting families to make informed decisions.
- Continued professional development specifically on working with families to support informed decision-making.
- A care pathway that highlights the importance of parents receiving the companion materials to this publication – *Helping you choose: making informed choices for you and your child*.

Section five: Additional materials and resources

The resources listed here are not necessarily about Informed Choice: they are resources that support the practice examples highlighted in this handbook. The function of the resources is to help support services in moving towards a position of Informed Choice.

Key documents

British Association of Audiological Physicians (BAAP)

www.baap.org.uk

Paediatric Audiological Medicine (1990)

Guidelines for aetiological investigation of children with hearing loss (2001)

Department for Education and Skills

www.dfes.gov.uk

Developing Early Intervention/Support Services for Deaf Children and their Families (2003)

Department of Health

www.dh.gov.uk

National Service Framework for children, young people and maternity services (2004)

Core standards

Standards for Hospital Services

Early Support

www.earlysupport.org.uk

Service Audit Tool (2004)

Early Support Information for parents: Deafness (2004)

Helping you choose: making informed choices for you and your child (2006)



Modernising Children's Hearing Aid Services

www.mchas.man.ac.uk

Guidelines for the Fitting, Verification and Evaluation of digital signal processing hearing aids within a Children's Hearing Aid Service (2005)

Evaluation of children's hearing aids (2005)

Guidelines for the Taking of Impressions and Provision of Ear Moulds within a Children's Hearing Aid Service (2005)

Guidelines for testing Digital Signal Processing Hearing Aids 'In the Field' within an integrated Children's Hearing Aid Service (2005)

Guidelines for FM Systems (2005)

Guidelines for Professional Links between Audiology and Education Services within a Children's Hearing Aid Service (2005)

The National Deaf Children's Society

www.ndcs.org.uk

Information Publications

Deaf role model project

Family Sign Language Curriculum

Quality Standards in the Early Years: Guidelines on working with deaf children under two years old and their families (2002)

www.ndcs.org.uk/information

Family support network

www.ndcs.org.uk/our_services

Local Deaf Children's Societies (DCSs)

Parent Place

www.ndcs.org.uk

National Institute for Clinical Excellence (NICE)

www.nice.org.uk

Clinical Guidelines

Newborn Hearing Screening Programme

www.nhsp.info

Patient Journey protocols

Empowering and supporting parents through effective communication

NHS Modernisation Agency

www.modern.nhs.uk

Action on ENT – access and innovation (2002)

NHS Purchasing and Supply Agency

www.pasa.doh.gov.uk

NHS Purchasing and Supply Agency Briefing Paper on Provision (2004)

www.pasa.doh.gov.uk/audiology

The Royal National Institute for Deaf People

www.rnid.org.uk

Using Residual Hearing Effectively (CD-ROM)

Teachernet

www.teachernet.gov.uk

Continuing Professional Development (CPD) guide



Additional resources

Communication options in the education of deaf children

Lynas

Whurr (1994)

Guidelines and recommendations for testing and interpretations of CX26 mutations

Mazzoli, Murgia, Bitner, Gasparini, Read and Parving

Audiological Medicine 2(2): 139–40 (2004)

The benefits of mutual support groups for parents of children with disabilities

Solomon, Pistrang and Barker

American journal of community psychology, vol 29, No 1 (2001)

Factors contributing to the survival of self-help groups

Wituk, Shepherd, Warren and Meissen

American journal of community psychology, vol 29, No 1 (2002)

How these guidelines were produced

The National Deaf Children's Society, working with The University of Manchester, have collaborated with three groups of service providers and parents of deaf children in the production of these guidelines. These partnerships reflect the complexity of the multi-professional service context and the diversity of parent experience in which policy and practice initiatives, underpinned by research, seek to be effective.

In the production of these guidelines, the team⁶ initially engaged in a series of consultation events with parents and professionals from three very different service contexts:

- A metropolitan authority encompassing large minority ethnic communities and where a range of approaches to the education of deaf children co-existed, but were not necessarily perceived as co-operative within a co-ordinated approach for families.
- A medium-sized shire county offering a range of communication approaches, within the context of a strong history of a natural-aural approach, who are seeking to ensure that families are offered an Informed Choice with respect to provision of services.
- A group of services across a large region, who because of geography were grouped together, but whose membership reflected very different approaches to working with families and significant variation in available resources.

This diversity of context and service history provided rich experience for the consultation phases of the project.

In phase one, multi-professional groups and parent groups in each area met separately for day-long facilitated events that explored: professional and parent understandings of Informed Choice; current barriers and enablers of Informed Choice for families with deaf children; and the implications in practice of an Informed Choice approach to parent-professional working partnerships.

⁶ 'Team' refers throughout to staff from NDCS and from The University of Manchester together



A total of 27 parents and 47 professionals participated in this phase of the consultation. Overall, four languages (English, British Sign Language, Urdu and Punjabi) were used in the consultation days. Professional representation was drawn from education services, social services, audiology, health, and speech and language therapy. In addition there was representation from local deaf children's societies and Parent Partnerships. Both deaf and hearing professionals participated. Parents varied in their experience of services with most having deaf children within the birth to 6½ age range. Some of the deaf children also had disabilities.

All comments generated were recorded and treated formally as data, undergoing a detailed thematic content analysis. This analysis contributed directly to the identification and elaboration of the underpinning issues outlined in [Section two](#) of this document, as well as providing the bulk of the direct examples that illustrate these issues.⁷

Phase one consultation days were further extended by smaller cross-site meetings with strategic leads from different services, in order to gain further data on the strategic implications of moving towards an Informed Choice approach with families with deaf children.

Phase two consisted of joint parent and professional consultation days in which the major findings of the phase one days were fed back and comments invited. And parent and professional expectations of a guidance document were explored including issues of usability, format and fitness for purpose.

In phase three, parents and professionals received the full draft documents. Various local discussions took place and the team visited each site to receive structured feedback on the guidelines documents from both parents and professionals. This feedback contributed adjustments and amendments that were made prior to publication.

⁷ Full details of the research methodology, analysis approach and results from phase one consultation days can be found in the paper: *Informed choice, deaf children and families – underpinning ideas and project development*, published in the special edition of the Electronic Journal of Research in Educational Psychology (www.investigacion-psicopedagogica.org/revista)

In addition to this direct work with parents and professionals, the team undertook a meta-study of the concept 'informed choice' drawn from a wide range of research literature outside the field of deafness. Insights from this review⁸ assisted the facilitators on the consultation days, as well as feeding directly into the underpinning issues in [Section two](#) of this document.

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.



⁸ 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 existing 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 or to view any of the Early Support materials mentioned in this document, visit www.earlysupport.org.uk

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