CHAPTER NINE

Informed Choice and Deaf Children and Families

Alys Young, Gwen Carr, Ros Hunt, Wendy McCracken, Helen Tattersall

Why is Informed Choice an Issue?

It is commonly reported that an enduring experience of parenting a deaf child is that of choice and decision making (DesGeorges 2003; Young and Greally 2003). Whilst the same could be said of any parenting experience, in the context of deaf children and families it is an intensified process because of how deafness intersects with family life. For the vast majority of parents who are hearing, deafness is unfamiliar territory. This unfamiliarity consists both in a likely lack of knowledge about deafness, but also in a lack of prior relevancy to everyday life. Parents of deaf children will often describe experiences, people, contexts and ideas that they had absolutely no reason to consider of significance to how they led their everyday lives before they had a deaf child, as much as they might describe the acquisition of new knowledge, skills and information (Stredler Brown 2005; Young 1999; Young and Greally 2003). Deafness itself is a complex phenomenon attracting the involvement of vast range of professional service providers. Its implications are mutable and not easily predictable for how any individual deaf child may develop and thrive. Within society, to be deaf is itself prey to multiple, and not necessarily mutually exclusive, identity constructions, spanning impairment, disability and cultural-linguistic identity (Corker 1998; Gregory 2002; Ladd 2003; Lane, Hoffmeister and Behan 1996). As one hearing parent of a deaf child has astutely remarked: “How do I understand how deafness is understood?” (Young, Jones, Starmer and Sutherland 2005). Within such a maelstrom as this, we routinely require parents to engage in decision-making processes alongside professionals and to make choices on behalf of or with their deaf children that will in turn affect each child’s opportunities and choices as they grow up. Furthermore, with the advent of early identification of deafness, parents are routinely involved in choices for their deaf children from a far earlier stage in the parenting process than was previously the case, and for a much more sustained period of time (Luterman 2001; Young and Tattersall 2007).

However, in the English context, research studies have consistently shown that many hearing parents with deaf children perceive, with hindsight, that professional services did not make them fully aware of the range of choices available in supporting their deaf child’s linguistic and social development (Beazley and Moore 1995; Gregory 1976; Gregory, Bishop and Sheldon 1995; Young 2002; Young and Greally 2003; Young, Jones et al. 2005). Concern has primarily centered on communication choices with several varieties of experience and complaint: the provision of information that is regarded as biased; the withholding of information about particular communication options; the unequal weight given to one communication approach over another; the attitudinal bias of some professionals towards particular support options; the policy position of Local Authorities that limits the kind of communication intervention approach that is supported and offered to families. Communication choice is not the only issue, however. The attitude and orientation of professional services towards deafness

---

Address correspondence to: Alys Young PhD, MSc Oxon., MA Cantab., CQSW, Professor of Social Work Education and Research, University of Manchester, UK., Alys.Young@manchester.ac.uk.

1Some sections of this chapter first appeared in the “Journal of Deaf Studies and Deaf Education”, volume 11, 322–326, and are reproduced here with kind permission of Oxford University Press. Other sections are taken directly from the two handbooks on informed choice that were produced as part of the project and are reproduced here with kind permission of Early Support (the Department for Education and Skills).
itself has come under scrutiny (Beazley and Moore 1995). That is to say, parents report encountering predominantly medical models of deafness or deficit approaches in their early dealings with professional services, only to discover later cultural-linguistic models and alternative approaches to understanding the social identity/identities of their children (Young 2002). Though less well researched, there is also evidence to suggest that Deaf parents of Deaf children perceive choices concerning their children’s support to have been withheld from them. This is either because they are not offered, in the false belief that the information was not needed because parents were Deaf themselves, or because the information available was linguistically inaccessible to them (Young, Jones et al. 2005).

The issue raised by these experiences is not that a particular approach/attitude/position/option is of itself right or wrong. Rather concern centers around three related issues. Firstly, that parents may be making choices without having access to all relevant information and, therefore, lack an appropriate basis on which to make choices; secondly, that not all choices are available to all parents because some are denied, unacknowledged or not resourced; and thirdly that the professional – parent relationship is not an empowering one if the attitude and bias of the professional predominates. From these conclusions has come an increasingly strong call, in the UK context, for the promotion of policies and practices of informed choice in the provision of information and multi-professional services for families with deaf children.

In this chapter we describe a research and development project that was commissioned by the English government’s Department for Education and Skills (http://www.earlysupport.org.uk) in collaboration with the National Deaf Children’s Society (http://www.ndcs.org.uk) to: (i) investigate with professional service providers and parents, the provision and practice of informed choice in the specific context of deaf children, and (ii) to produce national guidelines in the form of practice handbooks for both professionals and parents.

**Investigating Informed Choice**

There were several key difficulties at the start of the project. Firstly, there was little clarity over what was meant by “informed choice” despite the phrase being in common usage. In many respects it was being defined by what it was not (e.g., impartial, poor information provision). The deafness-specific literature was sparse, and in its discussion of the issues of informed choice, rather restricted; informed choice tended only to be discussed in relation to communication choices. Furthermore, there was a widespread understanding that the focus of informed choice was the appropriate provision of quality information to enable choice, and very little else. Also, debates raged about whether informed choice was an appropriate goal to pursue in the first place. Amongst parents and professionals alike there are many passionate supporters of singular and particular choices, be it cochlear implants, auditory verbal therapy, sign bilingual provision and so forth. They are committed to some choices inherently being right and others not. Finally the relationship between parental participation in decision-making processes and the appropriate exercise of expert knowledge raised challenging questions about the very basis and style of parent/professional interaction.

**Method – First Stage**

Given the narrowly defined, conceptually contested and poorly researched nature of informed choice in relation to deafness, the first stage of the research project consisted of a comprehensive literature search to identify research studies concerning informed choice outside the direct field of deaf children and families. In analyzing this work a meta-study (Thorne, Jensen, Kearney, Noblit and Sandelooowski 2004) approach was employed. We use the term meta-study rather than meta analysis or meta synthesis to make the point that in reviewing the literature we were not attempting to aggregate, integrate, summarize or synthesize at the level of data as one might attempt in a systematic review, meta-ethnography (Noblit and Hare 1988), or meta analysis. Rather, we were concerned with deconstructing existing bodies of literature in order to reveal, at a conceptual level, the frames of reference, theoretical debates and interpretative arguments that were common to the wider body of literature on informed choice, regardless of the actual subject that might be being addressed by the study.

An electronic search was carried out using the search term “informed choice” across ten databases (MEDLINE 1966–2004; IBSS 1951–2004; ASSIA; Child Data; Sociological Abstracts; Social Services Abstracts; PsycINFO 1967–2004; Web of Science (Social Sciences Citation Index) 1956–2004; CINAHL 1982–2004; Social Sciences Index 1970–2004). This process resulted in 927 hits. The abstracts of these articles were read indepen-
dently by four members of the project team who isolated those articles considered most relevant to identifying the range of concepts and arguments associated with “informed choice”. Although such an inclusion criterion was wide and loosely defined, it was necessary given the focus on identifying relevance at a conceptual level, rather than at the level of research focus, method, or results. At the second stage, the full text of 152 selected articles was obtained. Each article was classified according to eight thematic groupings: content of information/information requirements; interface of the patient/person with the information; models of the information and choice relationship; requirements for the exercise of informed choice; roles and responsibilities of professionals/information providers; informed choice benefits; researching the existence/exercise of informed choice; and criticisms of informed choice as an approach. Concepts drawn from the articles relevant to each of these overarching themes were then initially recorded under these headings. The same article could be coded under more than one heading if there were several relevant concepts spanning more than one theme. These concepts were then further grouped and reorganized under the two main headings and seven subheadings: (i) The nature of information: “information that is evaluative not just descriptive”, “the difficulties of information for a purpose”, “the origins and status of information”, “informed choice and knowledge, not informed choice and information”. (ii) Parameters and definitions of choice: “informed choice as absolute and relative concept”, “preferences and presumptions of rationality”, “informed choice for whom?” For the complete elaboration of the results of this meta-study see Young et al. 2006.

Method – Second Stage

The second stage of data collection consisted of an iterative consultation process with parents (N = 27) and professionals (N = 47) in three varied family support service contexts. Participants were drawn from a wide range of disciplinary backgrounds including audiology, social work, speech and language therapy and education. Parents reflected varied familial and cultural backgrounds; four languages were used in the course of the consultation process (English, Punjabi, Urdu and British Sign Language).

The aims of the consultation process were: (i) to explore with participants what was understood by “informed choice”; (ii) to generate context specific examples of how it was experienced and where it was not experienced; (iii) to discuss barriers and facilitators of informed choice as way of practice (be it at strategic, organizational, or front line levels of interaction); and (iv) to provide on going consultation on the shape and delivery of the two final products. The consultation process was carried out on a group basis in half and full day sessions, repeated over a period of time as the project progressed from its initial exploratory stages to its development of the final product (the two handbooks for parents and professionals). For full details of the consultation method, service contexts, data collection and approach to analysis see Young, Hunt et al. 2005.

Selected Meta-Study Results

The meta-study results were subsequently used to delineate the underpinning issues that formed the conceptual basis of both the professional and parent handbooks. In what follows, selected results are presented from only three thematic areas of the meta-study: Information that is evaluative not just descriptive; informed choice and knowledge, not informed choice and information; and preferences and presumptions of rationality (see Young et al. 2006 for a complete elaboration of the theoretical basis of all thematic areas). Each is followed by the statement of the underpinning issues that became associated with this body of knowledge. How these underpinning issues were then used in the form and structure of the handbooks and the relationship of the underpinning issues with the data derived from the consultations is discussed in the third section of this chapter.

Information that is Evaluative not just Descriptive

Much of the literature surveyed reinforced the emphasis, also found in the deaf child literature, of the importance of providing information that is comprehensive, meaningful, relevant and unbiased if one seeks to enable people to make informed choices (Andrews 2000; Beaulieu 1999; Wagener and St. Clair 1989). However, there is in addition a well-developed set of arguments that draw attention to the fact that the provision of effective information to facilitate informed choice is not synonymous with information that could be regarded as neutral, or merely functionally descriptive. Rather, information that is evaluative is considered essential and in particular draws attention to the various risks and benefits of particular options. It is not just a case of understanding what the
range of choices might be, but also of understanding that in making one choice rather than another, one is also choosing an associated set of risks and benefits (Kuhn 2002; Westhoff 2001).

Within the medical literature on intervention and treatment regimes from which many such arguments are drawn, an emphasis on risk and benefit in information makes immediate sense. Potential side effects, rates of recovery, short and long term consequences for physical or mental functioning, success rates and so forth are graspable as objective variables about which data can be provided. However, evaluations of risk and benefit are much harder to define in relation to psychosocial interventions also common to the lives of parents of deaf children. Choice of communication approach, for example, does have implied risks and benefits in relation to social identity and how that is valued. It is not just a question of language or languages, but also of communities and cultures to which the child might ultimately belong and the consequences of so doing (Corker 1998; Lane et al. 1996). However, such complex kinds of potential consequence, mediated by so many other factors within familial, social and educational environments, are not ones that are readily amenable to straightforward approaches to risk/benefit analysis. Additionally, concerns have been raised about the extent to which concepts such as risk are well understood by the general public, or indeed health care providers in the first place (Kanell 1984). There is a growing industry of research into risk communication within treatment decision making (e.g., Edwards et al. 2003), with increasing acknowledgement that some kinds of risk understanding, e.g., physical consequences of a treatment, are more easily understood than others such as the possible psychosocial outcomes of a given decision (Godolphin, 2003).

More recently, the wider literature has placed considerable emphasis on the importance of the notion of uncertainty within an evaluative approach to information. Several studies have drawn attention to the importance of engaging choosers in the active understanding that it may not be possible to specify with full certainty, harm, risk, or indeed be definitive about benefit (Frewer et al. 2002). The nearest one might specify is degrees of uncertainty in certain domains. Indeed it is argued that without such inclusion of what is uncertain, then a situation is created of what Howard and Salkeld (2003) refer to as "information asymmetry" where risks and benefits may seem to be balanced but the true picture is distorted by only focusing on that which is confidently known.

Thus a considerable challenge is posed in designing information for parents of deaf children that might fulfil the condition of being evaluative of risk and benefits rather than merely descriptive of a range of options, and that is able to balance an appropriate emphasis on available evidence within a positive approach to uncertainty.

Informed Choice and Knowledge
Not Informed Choice and Information

It has been suggested that “informed choice” is rather a misnomer because the crucial relationship is not that between information and choice, but between knowledge/understanding and choice (Baker, Uus, Bamford and Marteau 2004; Kohut, Dewey and Love 2002; Marteau, Dormandy and Michie 2001). Smoking addiction and cessation provides a pertinent example (see Bailey 2004 for comprehensive review). It has been argued that if people are given clear and accurate information portraying facts about the health risks of smoking and still choose to do so, then they are making an informed choice and exercising their essential right to behave as they wish. However, the provision of information does not necessarily assure understanding. A study of young people and smoking demonstrated very poor levels of knowledge and understanding about risks and consequences and significant misinformation about smoking (Leventhal, Glynn and Fleming 1987). In these circumstances could one say young people were making an informed choice to smoke (nobody was forcing their hand), as the smoking industry would argue?

This focus on the degree of knowledge and understanding, rather than extent of information provision, in making informed choices has proved directive in domains such as the provision of materials to facilitate informed consent and behaviour prevention programs. In an aptly entitled paper ‘Just say no or just say know’ (Beck 1998) comparisons are made between drug prevention approaches that focus on encouraging young people making a deliberate choice to adopt an attitude not to take drugs (just say no) and those that seek to increase the extent of young people’s knowledge and understanding about drugs and their effects, based on which they may choose not to take drugs (just say know).

These debates about information and choice, or knowledge and choice draw important distinctions.
between informed choice as a statement of personal preference, with presumptions of individual rights of expression, and informed choice as a consequence of understanding, with presumptions of what might be adequate or required levels of knowledge in order to exercise it. As such, new questions are raised about who has the right to decide what are acceptable levels of understanding for whom (Hibbard, Jewett, Engelmann and Tusler 1998) and how might understanding be effectively promoted for those expected to make choices?

This insight into the promotion of knowledge and understanding to facilitate informed choice rather than the provision of information per se, raises significant challenges for practitioners working with families with deaf children. It draws attention to the importance of differences in parental learning styles (e.g., experiential or text-based), preferences in information use (e.g., comprehensive or phased); and variations in the extent to which parents are comfortable in initiating, questioning, seeking and communicating their needs (Young 2002; Young and Greally 2003). Working towards informed choice based on understanding rather than informed choice based on information provision remains a long-term challenge for parent and practitioner alike.

In the professional handbook on informed choice (DfES 2006a), the underpinning issues associated with the body of knowledge reviewed above were expressed as:

“I Need More than Information to Make a Choice

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

“It’s not Readily Available, but I Still Want to Know About it

Just because something isn’t available doesn’t mean that you shouldn’t know about it or that you can’t have it. You may have been told that what you want costs too much or that the professionals don’t have the right
preferences and Presumptions of Rationality

Informed choice as an approach has been criticized for its apparent assumptions of rational decision making (Burgess 1997), in which the individual, as in the Enlightenment ideal (Kant 1949), is assumed to be an independent, knowledgeable and autonomous being whose actions derive from that identity and who eschews all forms of paternalism (Klopmenhouter and Van den Belt 2003). Thus, it is the presentation of quality information in a skilled and supportive manner that enables patients/service users to reach an informed choice about a particular course of action. Yet we know that there are many factors that lead us to choices that one would not readily assume to be constituent of a strictly rational decision making approach (Burgess 1997; Ridley 2001) – gut instinct, culture, belief systems and values, as well as other aspects of familial, personal and social ecology.

Cullen (1999) describes the problem as one of failing to acknowledge the function of “proximal contingencies”. In other words, regardless of the alternatives and information available, engagement with informed choice must also be engagement with that which influences how an individual/family approaches the choices available (Carroll, Brown, Reid and Pugh 2000). As Marteau and Dormandy (2001) point out, an informed choice is not only defined by one based on good quality, relevant information, but also one that “reflects the decision maker’s values” (p. 185).

Other contingencies may have less to do with values and beliefs and more to do with socio-structural inequalities. Standing (1997), for example, explores how low income and the social construction of lone motherhood serve, in practice, to constrain children’s schooling choices, despite a wider range of school placements being theoretically equally available. The realities of poverty simply rule some of them out because of secondary consequences for the family (e.g., unaffordable travel costs depending on geographical location). Similarly, Schneider, Marschall, Roch and Teske (1999) explore the relationship between poverty and inequalities in access to information on which choices might be based. In ignoring such contingencies, the informed choice approach has been accused of perpetuating structural inequalities whilst seeming to extend the boundaries of personal choice (Standing 1997).

From a psychosocial point of view, there may also be barriers to effective engagement with an informed choice approach. A discussion of attempts to provide smoking cessation programs during pregnancy, for example, identified that mothers, in this case from low socio-economic backgrounds and facing a range of multiple stressors, needed help to acquire the necessary skills to raise their self esteem and assertiveness in order to make an informed choice in the first place (Ng 1997). The provision of information and promotion of autonomous decision making is not effective if other personal and contextual issues that might interfere with participation in a process of choice are not also addressed. Parents of deaf children, in common with many others, will quite naturally vary in their capacity to be choosers. They will quite naturally experience a range of psychosocial and economic structural barriers that can work both to inhibit some available choices and to render the very process of choice problematic. The challenge in framing early intervention within a discourse of informed choice is to balance the presumptions of rationality that underpin it with these personal and social realities.

In the professional handbook on informed choice (DfES 2006a), the underpinning issues associated with this body of knowledge were expressed as:

“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.”
“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 organized 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.”

“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’.”

In the parent handbook (DfES 2006b), the underpinning issues associated with this body of knowledge were expressed as:

“Informed Choice and Deaf Children and Families

Every Family is Different

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

“I Know my Family and Child Best

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

“I don’t Feel Comfortable and Confident about Making Choices

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

[For the full list of all underpinning issues in each handbook, which formed in their own right distinct sections, see DfES 2006a, b.]

Form and Content of the Handbooks

While the meta-study had successfully produced an issues-driven understanding of informed choice, for it to be made successfully relevant to the situation of deaf children and families, we also needed a context-driven understanding. This essentially is the role that the extended consultations with families and professional service providers played.

The Professional Handbook

From the analysis of the data derived from the consultation we were able to identify ten areas of professional practice where, from the point of view of service providers, specific help and guidance would be appreciated in moving towards a more informed choice approach to professional activity. These ten were: Appointments, Audiology, Communication, Family-to-Family Support, Information, Multi-agency working, Service Structure and Organization, Training, Transport. For each context area, there was a statement of principles, which applied one or more of the underpinning issues to the area of practice. That was then followed by informa-
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 judgments 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.”


The Parent Handbook

Consultations with parents, during which we shared results of the meta-study and the analysis of the context specific issues, led to significant discussions about the challenges involved in using that data to form the basis of a parent handbook. Parents identified to us five key challenges: (i) to make the idea of informed choice accessible and intelligible; (ii) to make it concrete and helpful; (iii) to provide a resource that was skills building as much as knowledge building; (iv) to respond to the huge variation in parents’ strengths, needs and capacities; (v) to provide a flexibly useable resource.

In responding to these challenges, the parent handbook was structured around twelve sections, each reflecting one of the underpinning issues in parents’ terms. The disparity between twelve issues for parents but fifteen for professionals reflects in some cases the merging of two issues for sake of clarity, and in others the de-emphasising of some issues that were not of comparable relevance, e.g., strategic planning for the allocation of resources within an informed choice framework. Having stated an underpinning issue in parents’ terms, this explanation is then followed by a short case study that is illustrative of the main points. These examples are then followed by things to think about, ideas for putting it into practice and further resources. Below is one example to illustrate the structure:

“It’s OK to Change my Mind

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

“What Helpful Things can be Learned from Jacob’s Story?

- Value your own knowledge and experience.
- Make time to consider whether previous choices still feel right for you and your family.
- Talk things over with other family members.
You may want to ask your keyworker or another professional to help you re-evaluate some of the choices you’ve made.

Consider whether this is the right time to look at other options which you haven’t thought about previously.

Don’t blame yourself if a previous choice now seems to have been wrong. You made the best decision you could at the time.

Monitor your child’s development with the professionals who support you, talking about what this means for choices in the past, present and future.”

Structuring the parents’ handbook in this way meant that we were able to reflect a huge diversity in the examples we used, thus appealing to a range of familial and deafness-related situations including cultural diversity, deafness with disabilities, variations in language use and preference, new device technologies and encounters with the full range of service providers, as well as the significance of other parents. The format also introduces knowledge and new ideas in a non-didactic way; engages parents in “like me” and “not like me” discussions without any judgments; introduces both thinking and doing tools; and allows access to information at different levels of understanding and preference. For example, for some parents the statement of the underpinning issue will be of little concern, preferring a more practical example. For others the case study approach may be alienating, preferring a less context dependent statement of the subject. The handbook ends with a parents’ checklist of how they know whether they have been offered an informed choice approach in their contact with professional services. In practice the whole document can be used on an individual basis by a parent, in parent-to-parent group discussions, and in conjunction with a professional such as an early interventionist or keyworker.

Copies of the parent handbook are available in pdf from www.earlysupport.org.uk under the title: “Helping You Choose. Making Informed Choices for You and Your Child” (DfES, 2006b). A version is also available in BSL (British Sign Language) on DVD.

Conclusion

This project grew from a unique partnership between a national organization working for parents of deaf children (NDCS) and a university research group. NDCS, however, were not absent commissioners of research; they were equal partners in the production of the research knowledge. Three members of the full informed choice project team worked for NDCS. Their close links with parents and current service provision were vital to the processes of consultation and interpretation of data. Likewise, three out of the four members of the team based in the university were also qualified practitioners who had worked in deafness-related services as well as being academic researchers (the fourth had deafness in the family as well as being a researcher). This mix of expertise and perspective was the bedrock of our issues-driven and context-driven approach to understanding informed choice and greatly influenced a research style that mixed theoretical analysis with empirically derived knowledge. As we write, a new training program on informed choice based on the project and its materials is being made available on a national basis – a further example of how informed choice is fundamentally a dynamic process, not a static outcome.

Acknowledgements

The full team who worked on the Informed Choice Project including the data collection/analysis and development of the materials that were a product from the project comprised: Alys Young, Gwen Carr, Anne-Marie Hall, Ros Hunt, Wendy McCracken, Amy Skipp, Helen Tatter...
sall. At the time Carr, Hall and Skipp worked for the National Deaf Children’s Society. The project was a joint undertaking by the National Deaf Children’s Society with the University of Manchester, funded by the Department for Education and Skills, Early Support programme.

The views contained in this article are those of the authors and not necessarily those of the Department for Education and Skills who funded this work.

References


