Informed Choice and Deaf Children: Underpinning Concepts and Enduring Challenges

Alys Young
University of Manchester

Amy Skipp
National Deaf Children's Society

Gwen Carr
National Deaf Children's Society

Helen Tattersall
University of Manchester

Ros Hunt
Wendy McCracken
University of Manchester

This article concerns the first stage of a research and development project that aimed to produce both parent and professional guidelines on the promotion and provision of informed choice for families with deaf children. It begins with a theoretical discussion of the problems associated with the concept of informed choice and deaf child services and then focuses specifically on why a metastudy approach was employed to address both the overcontextualized debate about informed choice when applied to deaf children and the problems associated with its investigation in practice with families and professionals. It presents a detailed analysis of the conceptual relevance of a range of identified studies "outside" the field of deafness. These are ordered according to 2 main conceptual categories and 7 subcategories—(a) the nature of information: "information that is evaluative, not just descriptive"; "the difficulties of information for a purpose"; "the origins and status of information"; and "informed choice and knowledge, not informed choice and information" and (b) parameters and definitions of choice: "informed choice as absolute and relative concept", "preferences and presumptions of rationality", and "informed choice for whom?" Relevant deaf child literature is integrated into the discussion of each conceptual debate in order both to expand and challenge current usage of informed choice as applied to deaf children and families and to delineate possible directions in the planning of the next stage of the main project aimed at producing parent/professional guidelines.

This article concerns a major review project that formed the first stage of a national (England) research and development project to produce policy and practice guidelines on "informed choice" in service provision for families with deaf children (birth to 3 years). It focuses in particular on how and why a metastudy approach (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004) to informed choice *outside* the field of deaf children and families was employed in preparation for primary data collection. The authors argue that in order to maximize the exploratory, consultative approach they wished to take in the main study, a means was required to challenge the overcontextualized meanings attributed to informed choice among parents and professionals in the deafness field, as well as among themselves. The conceptual issues identified from the metastudy are then discussed for their relevance to the deaf child and family context. In this way, a theoretically critical dialogue is created about the terms of engagement of the research project with the objective of the research. It is further suggested that the emergent frameworks play a role in informing the quality and scope of the subsequent data collection from families and professionals, as well as the interpretative analysis that will be performed on future data. The article begins, however, with a discussion of the background to informed choice for families with deaf children and why it has emerged as an issue of concern.

Background

Over the past 30 years, research studies in the U.K. context have consistently shown that many hearing

Correspondence should be sent to Alys Young, School of Nursing, Midwifery and Social Work, Coupland III Building, University of Manchester, Oxford Road, Manchester M13 9PL, United Kingdom (e-mail: alys.young@manchester.ac.uk).

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 & Moore, 1995; Elewke & Rodda, 2000; Gregory, 1976; Gregory, Bishop, & Sheldon, 1995; Young, 2003; Young & Greally, 2003; Young, Jones, Starmer, & Sutherland, 2005). Concern primarily centers 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 toward particular support options, and the policy position of local education authorities that limit 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 toward *deafness* itself comes under scrutiny (Beazley & Moore, 1995; Elewke & Rodda, 2000; Young, 2002). 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 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 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. First, that parents may be making choices without having access to all relevant information and, therefore, lack an appropriate basis on which to make choices; second, that not all choices are available to all parents because some are denied, unacknowledged, or not resourced; third, 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 U.K. context, for the policy and practice of informed choice in the provision of information and multiprofessional services for families with deaf children. This position has been encouraged by the introduction of universal newborn hearing screening (http://www.nhsp.info) and a strong current focus on early years' support for all disabled children (http://www.earlysupport.org.uk).

However, this framing of the issue as one of informed choice and the positioning of parents as empowered choosers are not without their own controversies. There is some evidence from parents themselves that they do not necessarily want an approach from professionals that seeks to empower them to make decisions for their children. Rather, an expert model in which professionals guide them to what is best for their child is welcomed. It can work to take away anxiety that they, as parents, might not be doing the right thing (Dale, 1996; Powers et al., 1999). Also, questions have been raised, particularly with regard to communication choices, whether an approach of unbiased information and equivalence of choice simply misses the point. Namely, that the parents' rights, enshrined in such an informed choice model, may actually bias and impede the deaf child's rights and potentially do harm (Hyde, 2004). This is a position most clearly seen with regard to sign language and Deaf culture where it is argued that these are the child's heritage and right, with visual language argued to be the child's most accessible and natural language (Kyle, 1994). Consequently, an education policy requiring sign language for all deaf children is promoted to ensure that this choice for the deaf child can be made in circumstances where hearing parents may not share the same perspective, by virtue of being hearing. Also among parents themselves, there are many passionate supporters of singular and particular choices, be it cochlear implants, auditory verbal therapy, bilingual provision, and so forth. They are committed to some choices inherently being right and others not. Thus, the presentation of different approaches to deafness and communication as equally valid is regarded as a travesty of the evidence.

Against this background, the Department for Education and Skills and Department of Health in

England, in their joint approach to improving services for families with deaf children from birth to 3 years (Department for Education and Skills/Department of Health, 2003), have come out strongly in favor of an informed choice approach. As part of this initiative, they commissioned the National Deaf Children's Society (NDCS), which is an organization representing parents of deaf children (http://www.ndcs.org.uk), to produce guidelines on the provision of informed choice. These were to be aimed at both parents and multiprofessional service providers. To achieve this end, NDCS decided to work in partnership with a university department to design and execute a research and development project aimed at producing such guidelines. In effect, NDCS did not want to write these as a piece of commissioned policy work but rather to set up an evidence base from which to inform the work of writing the guidelines.

In this article, we consider the fundamental first stage of that project, in particular the primary step of evaluating available literature. We identify the particular problem we encountered in seeking guidance from the literature, outline the rationale and results of a metastudy approach taken within literature "that had nothing to do with deafness or deaf children," and then consider its implications for the deaf child context in which we were to be developing guidelines on the provision and practice of informed choice.

Methodology

The Problem

In approaching the informed choice guidelines project, the research team identified three major problems. First, the literature available on informed choice and deaf children was highly parochial. That is to say, not only did it but rarely consider its central concept (informed choice) beyond its own subject-specific boundaries but also approaches within its own context were themselves self-consciously partisan. It was not just the case that arguments raged about whether informed choice for families with deaf children was an appropriate approach to pursue. It was that these arguments were generally more revealing of contested attitudes to deafness and deaf children rather than contested attitudes toward informed choice. It was hard to disentangle the constituent parts of what we might mean by the provision of informed choice from how stakeholders "conceptualized" a deaf child and, therefore, the associated rights of that child and his or her family. For shorthand's sake, we termed this situation the over-contextualization of informed choice.

The second difficulty looked ahead to primary data collection but also related to the rather narrow and highly context-specific terms in which the issues thus far had been debated. We were envisaging, in subsequent stages, a research design based firmly on consultation with service providers and service users (i.e., parents). With them we would explore, using focus group methods, the meanings, experiences, and implications associated with informed choice, including their perceptions of barriers and drivers to successful implementation of informed choice policy and practice. For this approach to be successful, however, we needed to equip ourselves with a good conceptual understanding of what was meant by informed choice, both at a theoretical/philosophical level and at a practice level. Whether for the facilitation of group discussions, the challenge of received meanings, or the interpretation of the range of understandings, our qualitative data would reveal that complex conceptual tools were needed. Yet this was precisely what the literature in our own field could not deliver. It was too narrow in its scope and too factional in its outlook.

The third problem related to us as a research team. We were not objective observers somehow disconnected with the deaf context. All of us have been highly embedded for many years in the world of deaf children and families, be it from differing positions of interest. In addition to our research identities, we also encompass within the team professional and personal identities, which included those of social worker, teacher of the deaf, Child of Deaf Adult, audiologist, interpreter, and child language specialist. Thus, we too needed our assumptions challenged and expanded about what we meant when we talked about informed choice if we were not to run the risk of simply reinforcing, without questioning, the assumptions and beliefs that for each of us orbited around that term.

The Approach

In response to these challenges, a comprehensive literature search was carried out to identify research studies concerning informed choice, but outside the direct field of deaf children and families. In analyzing this work (and as contained in this article), a metastudy (Thorne et al., 2004) approach was employed. We use the term metastudy rather than meta-analysis or metasynthesis 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, metaethnography (Noblit & Hare, 1988), metasynthesis, 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 addressed by the study. In this respect, we borrow the term "metastudy" as used by Thorne et al. (2004), which in its original usage describes the tripartite approach of metatheory, metamethod, and metadata to differentiate the alternative levels at which a metastudy might be undertaken. Distancing herself from meta-approaches that employ "a technique for synthesizing powerful new products" (Thorne et al., 2004, p. 1357), she points out that

> ...the more thoroughly you have examined the methodological, disciplinary and theoretical underbelly of the existing body of knowledge about a phenomenon, the more difficult it can become to make definitive claims about its nature. (p. 1357)

Such critical questioning and potential for conceptual differentiation around the phenomenon of informed choice was exactly what we sought.

The Method

An electronic search was carried out using the search term "informed choice" across 10 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, and Social Sciences Index 1970–2004). This process resulted in 927 hits. The abstracts of these articles were read independently 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. This process resulted in the selection of 152 articles. 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, methods, or results. At the second stage, the full text of 152 selected articles was obtained. Each article was classified according to eight thematic groupings. These themes were generated by the principal researcher in discussion with the research team, that is, she proposed the thematic categorizations based on recurring conceptual issues in the identified literature, and these were refined by the group. The eight thematic groupings were 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. Following further detailed reading of the selected articles, these concepts were then further grouped and reorganized under the two main headings and seven subheadings found in this article—(a) the nature of information: "information that is evaluative, not just descriptive"; "the difficulties of information for a purpose"; "the origins and status of information"; and "informed choice and knowledge, not informed choice and information" and (b) parameters and definitions of choice: "informed choice as absolute and relative concept"; "preferences and presumptions of rationality"; and "informed choice for whom?"

The following results section presents the identified arguments/concepts under each heading, seeking to map the conceptual territory in its own right separately from considering the relevance to the deaf child and family context. Reflections on the implications of the concepts and issues identified for informed choice and deaf children are then discussed in association with each section, rather than at the end in a stand-alone discussion section.

The Thematic Concepts Identified and Discussed

The Nature of Information

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; Wagner & St. Clair, 1989). However, there is in addition a well-developed set of arguments that draws 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, information that 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 a case of understanding that in making one choice rather than another, one is also choosing an associated set of risks and benefits (Kuhn, 2002; Rosser, Watt, & Entwistle, 1996; Westhoff, 2001).

Within the medical literature on intervention and treatment regimens from which much of such arguments are drawn, an emphasis on risks and benefits 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 risks and benefits are much harder to define and grasp in relation to psychosocial interventions,

such as those 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 a question of communities and cultures to which the child might ultimately belong and the consequences of doing so. However, such complex kinds of potential consequences, 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. A considerable challenge is posed in designing information for parents of deaf children that might fulfill the condition of being evaluative of risks and benefits rather than merely descriptive of a range of options.

However, 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 the harm or 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, 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.

Furthermore, 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). Indeed, there is a growing industry of research into risk communication within treatment decision making (e.g., Edwards et al., 2003), with increasing acknowledgment that some kinds of risk understanding, for example, physical consequences of a treatment, are more easily understood than others, such as the possible psychosocial outcomes of a given decision (Godolphin, 2003).

Within the deafness field, and in particular information provision to parents, these arguments concerning the importance of uncertainty understanding may

at first sight seem fitting. It is commonly remarked that every deaf child and his or her family is different. Predicting, therefore, with any certainty the likely effects and consequences of a particular course of action is notoriously difficult. Although with the advent of universal newborn hearing screening, some rigorous studies into child language and social outcomes are being undertaken (Moeller, 2000; Yoshinaga-Itano, 2003), we still do not have a particularly good evidence base for the effectiveness of some of the most basic interventions about which we routinely ask parents to make decisions. What is likely to work, for which children in which circumstances does remain uncertain. However, in many instances it remains uncertain because we do not have good evidence, rather than because we are unable to know. It remains a considerable challenge to provide parents with evidence-based information in which not only are degrees and types of uncertainty explained but also reasons for why that uncertainty might exist are discussed.

Of help in this respect, perhaps, is the concern in the wider informed choice literature on futures research. As May (1997) eloquently points out, our past will always be in the singular, 'we have only had one', but our future (viewed from the present) will always be in the plural. As such, we are all engaged in a form of "futures research" in making informed choices. Consequently, a crucial condition in information provision associated with informed choice must be the conveying of information concerning the range of consequences and outcomes (as far as these might be predicted) in making one kind of choice and not another or one kind of choice in the presence of another. In this respect, Amara (1981) distinguishes between "possible," "probable," and "preferable" futures dependent on present choices. Perhaps such an orientation is one of the ways that it might be possible to reframe a risk/benefit analysis approach while ensuring the evaluative nature of the information provided to facilitate informed choices. Certainly, a futures orientation is one commonly encountered in the narratives of parents of deaf children (Fletcher, 1987; Robinson, 1991). Attempts to envisage who my child will be and anxieties about what my child may or may not become are early and enduring considerations (Young & Greally, 2003) and a significant component of the basis on which parents make some choices and exclude others.

The difficulties of information for a purpose. The discussion thus far has tended to assume that issues associated with the nature of information are, in a broad sense, technical with certain matters one needs to address to "get it right." But of course, the provision of information to promote potential choice is not a technical activity; it is a form of purposeful discourse that takes place within a social and political context (Kerr, 2003), a problem discussed to a greater extent in the Parameters and Definitions of Choice. The question arises therefore of a tension between the provision of information to promote informed choice and the provision of information to promote participation in a particular activity, the benefits of which may already have been accepted as health or social good. In this respect, the recurring example in the literature concerns various forms of screening for particular health-related conditions (Marteau & Kinmouth, 2002; Raffle, 2001).

It has been argued that the overriding public health imperative leads to information strategies that tend to emphasize the benefits and neglect possible harms or uncertainties in an aim to maximize take up. Although the public generally receive good information to promote their understanding of the screening program and within that always have an option to participate or decline, such informed choice nonetheless occurs within contexts where the public health imperative is already established by dint of there being a screening program. Recently, in the United Kingdom, there has been a definitive policy shift in relation to all screening programs from the provision of information to maximize participation and emphasize public health to one of informed participation in which information is provided within a clear framework of informed choice (Marteau & Kinmouth, 2002). Nonetheless, it is still argued that information framed to maximize participation may in fact masquerade as information designed to promote informed choice (Sarfati, Howden-Chapman, Woodward, & Salamond, 1998).

Turning to the deaf child and family context, this distinction between information to maximize involvement in something already identified as desirable and

information to promote informed participation is a very familiar one. Particularly in relation to communication choices, proponents of specific approaches or methods commonly supply excellent information to parents about a given option on the basis of which it is assumed that parents are able to make decisions whether to adopt that approach or not. Indeed, some communication method-specific organizations in the United Kingdom see no conflict between information they supply and the promotion of informed choice. The argument runs that they are suppliers of high-quality information about one of the available choices open to parents and it is not their business to supply information about others that their organization may not support or may regard as potentially damaging. This position makes two assumptions: First that parental understanding of the spectrum of available choices is a process that occurs separately from engagement with any particular piece of literature and second that information to promote a specific option is clearly identifiable and understandable for what it is. Yet recurring findings in research with families with deaf children concern the difficulties that many families experience in gathering information about the available choices (Beazley & Moore, 1995; Steinberg, Bain, Li, Delgado, & Ruperto, 2003); later feelings of betrayal and anger that they had not known at the time that there were more choices available than the ones they made (Gregory et al., 1995); and for some families, not even knowing they had choices in the first place (Young et al., 2006). In other words, as the discourse of informed choice grows in the context of deaf children and their families, the place of information for purpose becomes one that requires considerable thought if specialist information is to fulfill its function but not masquerade as information to promote informed choice.

The origins and status of information.   With regard to the nature of information, there is considerable emphasis in the literature on the status and origins of the information that is provided. There are three related issues. First, whether the information provided is accurate, up-to-date, and evidence based (Andrews, 2000; Gattellari & Ward, 2003; Mühlhauser & Berger, 2000), although once again uncertainty is important in

referring to evidence. Second, there are quite simply some subjects about which there are more extensive evidence bases than others, although what counts as evidence is not necessarily straightforward. How much weight should be given to personal reports of patient's experiences in comparison with figures for the reduction in the size of a tumor? Third, if the emphasis on understanding risks, benefits, uncertainty, outcomes, and consequences is so crucial in the process of informed choice, then enabling information users to be able in some way to evaluate the strengths and weaknesses of the evidence on which information is provided must also be important. Clearly, not all patients/service users are going to have (or indeed want to have) critical skills to engage in such analysis, but how much information can be *trusted* is a reasonable and commonsense response to those seeking to understand possibilities and make difficult choices. Recent works on decision-making models, informed decision making (Sellers & Ross, 2003), evidence-based patient choice (Ford, Schofield, & Hope, 2003), and shared decision making (Emery, 2001; White, Keller, & Horrigan, 2003) have all made considerable inroads into providing practical ways to facilitate such critical engagement on accessible terms for patients/service users.

However, in the context of deaf children and families and the structuring of professional–parent interaction, there is little comparable work. Increasingly, the tenor of information to parents does draw attention to the range of factors parents might want to consider in making choices (e.g., Department for Education and Skills/Department of Health, 2004), but such approaches can provoke frustration. Although they may highlight what to think about and summarize available evidence, they provide little guidance on how to use consideration of these factors in actually making decisions (Young et al., 2005). Perhaps a fruitful area of future consideration might be whether the increasing popularity of decision-making model approaches in the wider context should also prompt their development in working with parents of deaf children?

Informed choice and understanding, not informed choice and information.   Finally, it has been suggested that informed choice is rather a misnomer because the

crucial relationship is not that between information and choice but that between knowledge/understanding and choice (Baker, Uus, Bamford, & Marteau, 2004; Kohut, Dewey, & Love, 2002; Marteau, Dormandy, & 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 start 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, & 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 the extent of information provision, in making informed choices has proved directive in domains such as the provision of materials to facilitate informed consent and behavior 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 to make 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, & Tusler, 1998) and how might under-

standing 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. However, it is debatable whether these challenges are in any way different than those faced in parent–professional partnerships in other spheres. Key issues remain the same such as differences in learning styles; preferences in information use (Young, 2002); and variations in the extent to which parents are comfortable in initiating, questioning, seeking, and communicating their needs (Steinberg et al., 2003; Young & Greally, 2003). This recognition of family style in the process of making information and experience meaningful has led to a resurgence both in the United States and in the United Kingdom of family-centered or family-led professional practice in which choice is conceptualized as an organic process rather than a one-off decision-making event (Roush and Matkin, 1996; Stredler-Brown, 2005). Intervention is increasingly cast as an "art," with much of the artistry consisting of tuning into parents' preferred ways of doing things and following parents' lead. Working toward informed choice based on understanding rather than informed choice based on information remains a long-term challenge for the parent and the practitioner alike.

In the wider literature, these challenges have to some degree been addressed by seeking to explore and define the professional attributes in interaction with patients/service users that are most facilitative of informed choice. Some of this interest has focused on knowledge and training with a clear acknowledgment of the need for professionals themselves to be up-to-date, accurate, and evidence (research) based in the information they share with patients/service users (Andrews, 2000; Hostick, 1994). Other studies have focused more on the professional skills required to be effective enablers of informed choice (Levy, 1999a, 1999b; Stapleton, Kirkham, & Thomas, 2002). A study of communication between midwives and expectant mothers, for example, found that although there was considerable information giving and a clear emphasis on informed choice promoted by midwives, true

patient choice often failed to be realized because the style of professional–patient interaction was one that did not easily allow questions (Stapleton, Kirkham, Thomas, & Curtis, 2002).

Some of the professional skills recurrently highlighted are perhaps expected, such as the adoption of counseling and nondirective styles of interaction, including culturally sensitive communication in the context of decision making (Smart & Smart, 1997), as well as flexibility in meeting the variety of information needs of patients. Others are perhaps less immediately obvious, such as the importance of creating a "sense of security," a key finding from a study of informed choice in relation to early discharge from hospital after birth (Persson & Dykes, 2002).

In the context of the promotion of informed choice with families with deaf children, there remains a dearth of research that has paid close attention to styles of professional–parent interaction and facilitation in any way that is comparable with the fine-grained studies in other fields. Yet if, in the U.K. setting at least, informed choice is to be rolled out as a basis of professional service provision and a fundamental statement of parental right, there surely must be a follow-up research into its enactment and effectiveness as there has been in other fields.

Parameters and Definitions of Choice

Thus far, we have shied away from attempting to provide a definition or definitions of informed choice because, as is already evident, conceptually it exists and is used at many levels of discussion—for example, activity, goal, process, orientation, rhetorical device, and right. In this section, we attempt to move closer to a formulation of what might count as informed choice, by examining how its parameters are delineated and debated.

Informed choice as absolute and relative concept.   There is an extensive debate in the wider literature over whether informed choice is best regarded as an absolute or relative concept. That is to say, which is most relevant—to understand the extent to which the concept is desirable or achievable in a universal sense or to understand the extent to which it is possible or facil-

itated in a context-bound sense? The first leads us into philosophical and political debates of first-order concepts such as autonomy (Kent, 1996) and the second into considerations of situational ethics and the economic and professional realities of the practice context (not that either of these emphases are mutually exclusive).

For example, the case of collective versus individual rights raises difficult questions for the promotion of informed choice with an issue such as childhood vaccinations being a case in point. The greater public health good dictates the need to promote compliance to vaccination programs. Recent concerns in the United Kingdom over the possible consequences of the Measles, Mumps, and Rubella vaccination have turned the debate into one of individual rights to choose compliance. However, in individuals seeking to reduce the perceived risk to/for their own children, they are potentially raising the risk to others in the general population through reduction of the universal level of immunization (Fitzpatrick, 2004).

These examples essentially focus attention on the difficult relationship between individual and social responsibility. However, as Kerr (2003) reminds us, oft-cited criticism of the apparently overindividualist nature of the informed choice discourse can fail to appreciate the extent to which individuals *do* exercise social responsibility in their choices to participate within public health programs. Our apparently individual identities are in part formed by our social embeddedness (Parker, 2001).

This apparent tension between individual and social responsibilities in the exercise of informed choice is, in the deaf context, most clearly apparent in terms of resource allocation. In the U.K. context, as in many countries across the world, the range and extent of available provision is highly variable depending on geographical location. Parental choice of a support approach that might not readily be available and thus has to be sourced through extraordinary arrangements has consequences for other parents. If the choice is, for that single child, regarded as disproportionately expensive in comparison with the cost of children supported through locally available services, then the finite resource is, in global terms, reduced for others. However, there are obvious problems in framing the

argument in this way. It is a small step from asking parents to consider their social responsibility to other parents and in effect using this argument to restrict an individual's right of access to theoretically available, if not practically apparent, support options.

In the wider literature also, there is some debate, although it is rare, of the problems that arise when informed choice is promoted, but it is not necessarily the case that all options "could" be offered. Resources, lack of skills, or lack of service locally may preclude some desired service possibilities. A study of cognitive behavior therapy (CBT) for the treatment of social anxiety disorders (SADs), for example, concluded that patients' informed choice was by definition limited by the lack of availability of CBT therapists who worked with SAD (Radomsky & Otto, 2001). Faced with such an issue, what is more ethical: to embrace a duty to describe "non readily available alternatives" (Terrion, 1993) or to focus only on the available and achievable? After all, in many aspects of our lives, it is highly unusual to experience an unconstrained set of choices as many issues of personal and social context routinely set the limitations of our expectations and social behavior.

This is an ethical and practical dilemma that is very familiar to services working with families of deaf children. For example, in a given locality, there may not be primary intervenors comfortable or skilled in encouraging the full range of communication choices, budgets will set limits on the number of children who may go forward for cochlear implantation in any one year, it may not be possible to offer a quick turnaround earmold service because of shortage of trained staff, and so forth. The key question being faced, therefore, is whether the move to informed choice is setting up unrealistic expectations for families of services that could not necessarily be delivered or whether it is concentrating the mind on how to meet these expectations within the constraints of finite resources?

The absoluteness of the informed choice imperative is also questioned in terms of clinical decision making where interest centers on which (if any) aspects of treatment and care are amenable to patient choice and which are simply regarded as not and by whom. In effect, the clinician's expertise may set the diagnosis and treatment requirements, but within these parameters, there may be considerable scope for patients to

make informed choices about how that treatment is exercised (with attendant risks, benefits, uncertainties, and ranges of outcome consequences). Expressed in this manner, such a dichotomy between the negotiable and the nonnegotiable seems rather neat, but it is rather hard to maintain a distinction between subjects about which one can have an informed choice and the actual interpersonal dynamics involved in the choosing context. Decisions about what a patient should have informed choice about or not can in practice be mediated by the attitudes and approaches of both the clinician and the patient, not necessarily by the demands of the condition or circumstance (Godolphin, 2003).

In the deaf child context, the essential question of what is and what is not amenable to informed choice is played out in highly politicized terms. Answers to this question perhaps reveal less about whether and how an informed choice approach is supported and more perhaps about the framework in which a deaf child is being conceptualized. For example, is it possible for parents to make an informed choice to refuse hearing aids for their child? Would we feel equally strongly about parents who refuse sign language access as we might about parents who refuse hearing aids? Perhaps here the point is not so much where do professionals draw the line but are they being explicit about doing so and on what grounds. It is not necessarily unreasonable for informed choice to operate within parameters, but the problem is that these parameters in defining what is regarded as acceptable and unacceptable arenas of choice may also define values. Given the conflictual history of family support and deaf education more generally, tackling this issue of what is amenable to informed choice is a fundamental challenge to the approach being successful.

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 (Klompenhouweer & 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, values, family, financial circumstances, and so forth. How does an informed choice approach deal with such factors of personal and social ecology?

Cullen (1999) describes this 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, & Pugh, 2000). As Marteau and Dormandy (2001) point out, an informed choice is defined by not only one that is 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 sociostructural 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 wide 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 while 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 socioeconomic 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.

In these respects, the deaf child and family context is perhaps no different from any other. We know that a large number of parents of disabled children, in the U.K. context, experience significant poverty and social deprivation (Beresford, 1995; Dobson & Middleton, 1998) and the stresses and challenges of parenting a disabled child are considerably compounded by these factors (Joseph Rowntree Foundation, 2000). We know that cultural values and traditions play a significant role not just in positively framing preferences (Chamba, Ahmad, & Jones, 1998; Parasnis, 1997; Steinberg et al., 2003) but also in negatively engendering stereotypical discrimination (Ahmad, Darr, & Jones, 2000). It has long been appreciated that a common experience of parents of deaf children is to be thrust into situations where they are required to make many choices and to interact with professionals that hitherto they may have had no need or experience of. As such, parents often report that becoming that person who is required to engage in those interactions and choices is of itself a challenge to which not all feel able to rise (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Young & Greally, 2003). Thus, 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.

Informed choice for whom?   Previous discussions have drawn attention to the tension between individual rights and social responsibility. There is another element, however, to the problem of whom one might be making choices for, and this concerns the enduring ethical debates about the rights of the child and the

rights of parents/carers to make choices *on behalf of* the child. Informed choice in relation to issues of childhood illness and disability provides some of the most profound examples of the futures orientation of informed choice processes. In many examples of choosing among various intervention and support approaches, parents/carers find themselves choosing among different kinds of expectations of their children's futures, as well as among different varieties and degrees of uncertainty (Ward, 1998).

For some disabled adults, the drive for conventional appearance or normal functioning that underpinned the choices their able-bodied parents made on their behalf was, from their now adult perspective looking back, misguided (French, 1993). Surgeries that were endured often at great pain can come to be seen to have been abusive and the understanding on which choices were made for them a false understanding that failed to acknowledge their positive identity as disabled people within a diverse society (Shakespeare, 1998). In other words, in making informed choices on behalf of others (in this case children), the issue is not so much whose benefit do the consequences of those choices serve but rather whose version of benefit drives the basis on which those choices are made in the first place and indeed whose vision of the future.

As discussed earlier, in the context of deaf children, choices for the child and/or choices for the parents has been a cornerstone of the debate both in support of and in opposition to informed choice. Fundamental questions are raised by the Deaf community over whether hearing parents are actually equipped to engage in choices from the perspective of deafness and the deaf adult that their son or daughter will become (Ladd, 2003). However, the point of choices made in trust for and on behalf of a child is not just confined to the perspective of the signing Deaf community. Increasingly, parental choice on behalf of deaf children is being held up to critical account more broadly as an issue of the human rights of the deaf child. Hyde (2004), for example, draws attention to the concept of "open futures" in which the child's right to future autonomy including full access to all lifestyle choices is regarded as "rights in trust." If the rights of the family to exercise their own autonomy conflict with the future autonomy of the child, questions are thus raised about the obligations of society to intervene to protect the child's open future.

An emphasis on informed choice for the child and how it interacts with an understanding of parents' engagement in processes of informed choice is a major concern for practitioners and professionals alike. A focus on informed choice potentially enables this debate to move out of communication approach-specific positions and into the mainstream consciousness as a key basis of professional–parent interaction.

Conclusion

This article began by outlining our view that the debate surrounding informed choice and parents of deaf children had become overcontextualized and was being largely pursued in politically partisan terms. Our objectives were to broaden understanding by seeking relevance (if any) between the wider literature and the deaf child-specific context and to hold up to critical reflection our own assumptions as researchers that we would be taking into further phases of the project. The debates we have uncovered and the reflection we have engaged in have done much to reveal a range of key challenges. These are associated not just with the philosophical and political basis of informed choice in application to families with deaf children but also in terms of its implications for professional practice. Some of the latter are closely associated with understanding the strategic responsibilities that come with the appropriation of informed choice as a policy driver.

As authors and researchers, we have personally and collectively traveled a long distance. We have moved away from concerns over how to define the practice and promotion of informed choice to an integrated understanding of its implications in interaction with the personal and structural circumstances in which it seeks to be enacted. How the insights and debates of this stage of the project were subsequently played out in the phases of data collection, interpretation, and production of guidelines remains the subject of further articles (see Young et al., 2006). As we write, the professional and parent guidelines on informed choice are going to press and will be available via the government project Early Support (http://www.earlysupport.org.uk).

References

Ahmad, W. I. U., Darr, A., & Jones, L. (2000). "I send my child to school and he comes back an Englishman": Minority ethnic deaf people, identity politics and services. In W. I. U. Ahmad (Ed.), *Ethnicity, disability and chronic illness* (pp. 67–84). Buckingham, UK: Open University Press.

Amara, R. (1981, February). The futures field. Searching for definitions and boundaries. *The Futurist*, 25–29.

Andrews, G. (2000). Contraception: What has changed over the past decade? *British Journal of Nursing, 9,* 326–333.

Bailey, C. J. (2004). From 'informed choice' to 'social hygiene': Government control of cigarette smoking in the US. *Journal of America Studies, 38*(1), 41–65.

Baker, H., Uus, K., Bamford, J., & Marteau, T. M. (2004). Increasing knowledge about a screening test: Preliminary evaluation of structured, chart-based, screener presentation. *Patient Education and Counseling, 52,* 55–59.

Beaulieu, D. (1999). Organ donation: The family's right to make an informed choice. *Journal of Neuroscience Nursing, 31*(1), 37–45.

Beazley, S., & Moore, M. (1995). *Deaf children, their families and professionals: Dismantling the barriers.* London: David Fulton.

Beck, J. (1998). 100 Years of 'just say no' versus 'just say know'. Re-evaluating drug education goals for the coming century. *Evaluation Review, 22*(1), 15–45.

Beresford, B. (1995). *Expert opinions: A national survey of parents caring for a severely disabled child.* Bristol, UK: The Policy Press.

Burgess, R. (1997). Deconstructing drug prevention: Towards an alternative purpose. *Drugs: Education, Prevention and Policy, 4,* 271–283.

Carroll, J. C., Brown, J. B., Reid, A. J., & Pugh, R. (2000). Women's experience of maternal serum screening. *Canadian Family Physician, 46,* 614–620.

Chamba, R., Ahmad, W., & Jones, L. (1998). *Improving services for Asian deaf children: Parents' and professionals' perspectives.* Bristol, UK: The Policy Press.

Cullen, C. (1999). Contextualism in intellectual disability research: The case of choice behaviour. *Journal of Intellectual Disability Research, 43,* 437–444.

Dale, N. (1996) *Working with families of children with special needs: Partnership and practice.* London: Routledge.

Department for Education and Skills/Department of Health. (2003). *Developing early intervention/support services for deaf children and their families* (LEA/0068/2003). Retrieved May 7, 2006 from http://www.teachernet.gov.uk/docbank/index.cfm?id=5910 and http://www.earlysupport.org.uk

Department for Education and Skills/Department of Health. (2004). *Deafness. Information for parents.* Retrieved May 7, 2006 from http://www.earlysupport.org.uk/Default.aspx?tabid=88.

Dobson, B., & Middleton, S. (1998). *Paying to care: The cost of childhood disability.* York, UK: York Publishing Services.

Edwards, A., Elwyn, G., Hood, K., Robling, M., Atwell, C., Holmes-Rovner, M., et al. (2003). The development of COMRADE—A patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision main in consultations. *Patient Education and Counselling, 50,* 311–322.

Elewke, C. J., & Rodda, M. (2000). Factors contributing to parents' selection of a communication mode to use with their deaf children. *American Annals of the Deaf, 145,* 375–383.

Emery, J. (2001). Is informed choice in genetic testing a different breed of informed decision-making? A discussion paper. *Health Expectations, 4,* 81–86.

Fitzpatrick, M. (2004). MMR: Risk, choice, chance. *British Medical Bulletin, 69,* 143–153.

Fletcher, L. (1987). *Language for Ben: A deaf child's right to sign.* London: Souvenir Press.

Ford, S., Schofield, T., & Hope, T. (2003). What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. *Social Science and Medicine, 56,* 589–602.

French, S. (1993). Can you see the rainbow? In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers—Enabling environments.* London: Sage in association with Open University Press.

Frewer, L. J., Miles, S., Brennan, M., Kuznesof, S., Ness, M., & Ritson, C. (2002). Public preferences for informed choice under conditions of risk uncertainty. *Public Understanding of Science, 11,* 363–372.

Gattellari, M., & Ward, J. E. (2003). Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomised controlled trial. *Journal of Medical Screening, 10,* 27–39.

Godolphin, W. (2003). The role of risk communication in shared decision making. *British Medical Journal, 327,* 692–693.

Gregory, S. (1976). *The deaf child and his family.* Cambridge, UK: Cambridge University Press.

Gregory, S., Bishop, J., Sheldon, L. (1995). *Deaf Young People and their Families: Developing Understanding.* Cambridge, UK: Cambridge University Press.

Hibbard, J. H., Jewett, J. J., Engelmann, S., & Tusler, M. (1998, December). Can Medicare beneficiaries make informed choices? *Health Affairs,* 181–193.

Hostick, T. (1994). Accountability in mental health nursing. *British Journal of Nursing, 3,* 672–674.

Howard, K., & Salkeld, G. (2003). Home bowel cancer test and informed choice—Is current information sufficient? *Australian and New Zealand Journal of Public Health, 27,* 513–516.

Hyde, M. (2004, March). Ontario Infant Hearing & Communication Development Program—Approach & Issues. Paper presented at the National Newborn Hearing Screening Conference, London. Retrieved January 5, 2006 from http://www.nhsp.info

Joseph Rowntree Foundation. (2000). *Supporting disabled children and their families.* York, UK: Joseph Rowntree Foundation.

Kanell, R. G. (1984, September). Oral contraceptives: The risks in perspective. *Nurse Practitioner,* 25–62.

Kant, I. (1949). What is Enlightenment? In C. J. Friederich (Ed.), *The philosophy of Kant: Immanuel Kant's moral and political writings* (pp. 132–139). New York: The Modern Library.

Kent, M. A. (1996). The ethical arguments concerning the artificial ventilation of patients with motor neurone disease. *Nursing Ethics, 3,* 317–328.

Kerr, A. (2003). Rights and responsibilities in the new genetics era. *Critical Social Policy, 23*(2), 208–226.

Klompenhouweer, T., & Van den Belt, H. (2003). Regulating functional food in the European Union: Informed choice versus consumer protection. *Journal of Agricultural and Environmental Ethics, 16,* 545–556.

Kohut, R. J., Dewey, D., & Love, E. J. (2002). Women's knowledge of prenatal ultrasound and informed choice. *Journal of Genetic Counselling, 11,* 265–276.

Kuhn, L. (2002). Beyond informed choice: Infant feeding dilemmas for women in low-resource communities of high HIV prevalence. *Social Dynamics, 28*(1), 132–154.

Kyle, J. G. (1994). *Growing up in sign and word.* University of Bristol, United Kingdom: Centre for Deaf Studies.

Ladd, P. (2003). *In search of deafhood: Understanding Deaf culture.* Clevedon, UK: Multilingual Matters.

Leventhal, H., Glynn, K., & Fleming, R. (1987). Is the smoking decision an informed choice? Effect of smoking risk factors on smoking beliefs. *The Journal of the American Medical Association, 257,* 3373–3376.

Levy, V. (1999a). Maintaining equilibrium: A grounded theory study of the processes involved when women make informed choices during pregnancy. *Midwifery, 15,* 109–119.

Levy, V. (1999b). Protective steering: A grounded theory study of the processes by which midwives facilitate informed choices during pregnancy. *Journal of Advanced Nursing, 29*(1), 104–112.

Marteau, T. M., & Dormandy, E. (2001). Facilitating informed choice in prenatal testing: How well are we doing? *American Journal of Medical Genetics, 106,* 185–190.

Marteau, T. M., Dormandy, E., & Michie, S. (2001). A measure of informed choice. *Health Expectations, 1,* 99–108.

Marteau, T. M., & Kinmouth, A. L. (2002). Screening for cardiovascular risk: Public health imperative or matter for individual informed choice? *British Medical Journal, 325,* 78–80.

May, G. H. (1997). The Sisyphus factor or a learning approach to the future. *Futures, 29,* 229–241.

Meadow-Orlans, K. P., Mertens, D. M., & Sass-Lehrer, M. A. (2003). *Parents and their deaf children. The early years.* Washington, DC: Gallaudet University Press.

Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics, 106,* E43.

Mühlhauser, I., & Berger, M. (2000). Evidence-based patient information in diabetes. *Diabetic Medicine, 17,* 823–829.

Ng, N. (1997). Smoking cessation programme: An ethical analysis. *Modern Midwife, 7*(8), 23–27.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies.* Newbury Park, CA: Sage Publications.

Parasnis, I. (1997). Cultural identity and diversity in deaf education. *American Annals of the Deaf, 142*(2), 72–79.

Parker, M. (2001). The ethics of evidence-based patient choice. *Health Expectations, 4,* 87–91.

Persson, E. K., & Dykes, A. K. (2002). Parents' experience of early discharge from hospital after birth in Sweden. *Midwifery, 18,* 53–60.

Powers, S., Gregory, S., Lynas, W., McCracken, W., Watson, L., Boulton, A., et al. (1999). *A review of good practice in deaf education.* London: RNID.

Radomsky, A. S., & Otto, M. W. (2001). Cognitive-behavioural therapy for social anxiety disorder. *The Psychiatric Clinics of North America, 24,* 805–815.

Raffle, A. E. (2001). Information about screening—Is it to achieve high uptake or to ensure informed choice? *Health Expectations, 4,* 92–98.

Ridley, D. T. (2001). Informed consent, informed refusal, informed choice—What is it that makes a patient's medical treatment decisions informed? *Medicine and Law, 20,* 205–214.

Robinson, K. (1991). *Children of silence.* London: Penguin.

Rosser, J., Watt, I. S., & Entwistle, V. (1996). Informed choice initiative: An example of reaching users with evidence-based information. *Journal of Clinical Effectiveness, 1*(4), 143–145.

Roush, J., & Matkin, N. (Eds.). (1996). *Infants and toddlers with hearing loss: Family centred assessment and intervention.* Baltimore: York Press.

Sarfati, D., Howden-Chapman, P., Woodward, A., & Salamond, C. (1998). Does the frame affect the picture? A study into how attitudes to screening for cancer care affected by the way benefits are expressed. *Journal of Medical Screening, 5,* 137–140.

Schneider, M., Marschall, M., Roch, C., & Teske, P. (1999). Heuristics, low information rationality, and choosing public goods. Broken windows as shortcuts to information about school performance. *Urban Affairs Review, 34,* 729–741.

Sellers, D. B., & Ross, L. E. (2003). African American men, prostate cancer screening and informed decision making. *Journal of the National Medical Association, 95,* 618–625.

Shakespeare, T. (1998). Choices and rights: Eugenics, genetics and disability equality. *Disability and Society, 13,* 665–682.

Smart, J. F., & Smart, D. (1997). Culturally sensitive informed choice in rehabilitative counselling. *Journal of Applied Rehabilitation Counseling, 28*(2), 32–37.

Standing, K. (1997). Scrimping, saving and schooling. Lone mothers and 'choice' in education. *Critical Social Policy, 51*(17), 79–99.

Stapleton, H., Kirkham, M., & Thomas, G. (2002). Qualitative study of evidence based leaflets in maternity care. *British Medical Journal, 324,* 639–644.

Stapleton, H., Kirkham, M., Thomas, G., & Curtis, P. (2002). Language in antenatal consultation. *British Journal of Midwifery, 10*(5), 273–277.

Stredler-Brown, A. (2005). Family-centred intervention: Proven strategies to assure positive outcomes. In R. C. Seewald & J. M. Bamford (Eds.), *A sound foundation through early amplification 2004.* Proceedings of the Third International Conference Chicago, November 2004 (pp. 185–196).

Steinberg, A., Bain, L., Li, Y., Delgado, G., & Ruperto, V. (2003). Decisions Hispanic families make after the identification of deafness. *Journal of Deaf Studies and Deaf Education, 8,* 291–314.

Terrion, H. F. (1993). Informed choice: Physicians' duty to disclose non readily available alternatives. *Case Western Reserve Law Review, 43,* 491–523.

Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis: Reflections on methodological orientation and ideological agenda. *Qualitative Health Research, 14,* 1342–1365.

Wagner, M. G., & St. Clair, P. (1989, October). Are in-vitro fertilisation and embryo transfer of benefit to all? *The Lancet,* 1027–1029.

Ward, C. (1998). The treatment of craniosynostosis: An ethical perspective. *Cleft Palate—Craniofacial Journal, 35*(3), 212–214.

Westhoff, C. (2001). Criteria for appropriate birth control. *Gynecological Endocronology, 15*(Suppl. 3), 19–22.

White, M. K., Keller, V., & Horrigan, L. (2003). Beyond informed consent: The shared decision making process. *Journal of Clinical Outcomes Management, 10,* 323–328.

Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education, 8*(1), 11–30.

Young, A. M. (2002). Parents of deaf children—Factors affecting communication choice in the first year of life. *Deafness and Education International, 4*(1), 1–12.

Young, A. M. (2003). *Parenting and deaf children—A psychosocial literature based framework.* London: NDCS. (46 p). Retrieved January 14, 2006 from http://www.ndcs.org.uk

Young, A. M., & Greally, A. (2003). *Parenting and deaf children—Report of the needs assessment study.* London: NDCS. (114 p). Retrieved January 14, 2006 from http://www.ndcs.org.uk

Young, A. M., Hunt, R., Carr, G., Hall, A. M., McCracken, W., Skipp, A., et al. (2006). Informed choice, deaf children and families: Underpinning ideas and project development. *The Electronic Journal of Research in Educational Psychology, SEN Special Edition 7, 3*(3). Retrieved April 9, 2006 from http://www.investigacion-psicopedagogica.org/revista/

Young A. M., Jones, D., Starmer, C., & Sutherland, H. (2005). Issues and dilemmas in the production of standard information for parents of young deaf children—Parents' views. *Deafness and Education International, 7*(2), 63–76.