Parenting and Deaf Children - A psycho-social literature based framework.

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This literature review was commissioned by the National Deaf Children's Society (NDCS) as part one of a needs assessment and development study into parenting and deaf children. The review specifically relates to literature concerning hearing parents with deaf children. It was written by Dr Alys Young, University of Manchester (Human Communication and Deafness Group). Accompanying this work is a companion volume entitled *Parenting and deaf children: Report of the needs assessment study undertaken as part one of the NDCS Parents' Toolkit Development project.* This presents the results of a parents' survey and focus groups investigating the experiences of bringing up a deaf child. It is also published by NDCS.

In addition, a summary of the needs assessment study for parents is available from NDCS entitled *NDCS assessment study about parenting and deaf children: A summary.*

This information is available to individuals, on request, in large print, audio tape and in Braille.

The NDCS uses the term 'deaf' to cover all types of hearing loss, including temporary hearing loss such as glue ear.

Contents

Introduction

There is no shortage of literature on parents and deaf children. The past twenty years have seen an explosion of research into the impact and consequences of childhood deafness on parents and the family, and of parents and the family on deaf children's development. Key topics have included: stress and coping (Calderon and Greenberg, 1993); psychological adjustment, (Luterman, 1999); family functioning (Moores, 1987; Henggeler et al, 1990); early interaction (Gallaway and Woll, 1994); stress and social support (Meadow-Orlans, 1994; Quittner et al, 1990); language and communication development (Lynas, 1994; Reamy and Brackett, 1999); ethnicity and culture (Chambra, Ahmad and Jones 1998; Yacobacci-Tam, 1987); early intervention (Greenberg and Calderon, 1984; Stokes, 1999; Young, 1995); and parent/professional relationships (Beazley and Moore, 1995; Ling-Phillips, 1987; NDCS, 2000).

However, despite this abundance of literature, there is little work that specifically addresses the concept and practice of parenting within the context of deaf children. Granted, there are some very helpful books deliberately aimed at supporting parents understand childhood deafness, the new experiences it brings, and the demands it makes on parents (Freeman et al, 1981; Knight and Swanick, 1999; Marschark, 1997; McCracken and Sutherland, 1991; Naiman and Schein, 1978; Nolan and Tucker 1988; Ogden, 1997; Schwartz, 1996). But is this the same as a focus on parenting?

If by parenting we mean the skills, knowledge, roles, resources, experiences, qualities, values, tasks, and activities required to bring up a child successfully, then the problem in the context of deaf children is that we have very little idea of what 'normative' parenting might be. Too easily, the particular skills, knowledge and adaptations required to respond to the child's special needs can become in themselves the definition of parenting.

An obvious example of this process, and one encountered by many parents of deaf children, concerns the parental role in deaf children's language development. Based on good evidence that the more involved a parent is in encouraging their child's language development, then the more likely the child is to progress (Marschark, 1997), professionals exhort parents to become all sorts of different kinds of teachers and therapists with their children (Schwartz, 1996). However, there comes a point of realisation that other equally valuable aspects of being 'mum' or 'dad' have become lost or obscured by this 'transformed' parenting role (Luterman, 1999).

Similarly, as a parent of a deaf child, it is necessary to become familiar with all sorts of knowledge and make decisions that parents of hearing children are unlikely to have to do in the same way (Beazley and Moore, 1995). For example, the choice of communication method, the management of hearing aids, becoming familiar with a different culture (Deaf culture), are all largely deaf-child specific (McCracken and Sutherland, 1991). Activities such as these

may seem to become the defining features of the parenting role with deaf children, precisely because they lie outside most parents' usual "sphere of relevance" (Schutz, 1962). They are therefore seen to be both central to the role and requiring the acquisition of specific knowledge and competencies. But as Marschark (1997) and others have pointed out, deaf children require of their parents exactly the same things that hearing children do, although the means and process of providing those may be different.

Consequently, much of what it is to be a parent of a deaf child will share many features of what it is to be a parent of any child (Ogden, 1984):

> "…parents should feel reassured that most of what they need to 'know and do' is there within normal parenting skills and that it is possible for other new skills to be learnt and absorbed into the parenting role." (Knight and Swanwick, 1999, p.42)

In other words, the moment one tries to conceive of a framework in which to understand parenting and deaf children, one is confronted by a very real tension: namely, the complex relationship between the *specialing* of parenting [there are particular things you have to do, or do in a different way, because your child is deaf], and the *normalising* of parenting [parenting a deaf child is still parenting a child]. This is not just a neat academic tension in the research literature: it is also, by parents' own accounts, a significant daily reality, as they come to terms with both the

expected and the unexpected roles involved in being a parent of a deaf child (Moores, 1987; Morgan Redshaw et al, 1990).

The other problem in seeking to pin down what we might mean by parenting with deaf children is that much of what we know about parenting and deaf children is based on what we know goes wrong, rather than what we know goes right. For example, from the difficulties a considerable number of deaf children experience in psycho-social development (Greenberg and Kusche, 1993; Hindley, 1993b), it has been possible to identify the characteristics of less than optimum nurturing environments and to promote more positive ones. From the poor language development of many deaf children, it has also been possible to draw conclusions about parent-child interactive styles that do not work, and by corollary, those that do (Meadow-Orlans and Steinberg, 1993, Spencer, 1993).

However, studies that aim to draw conclusions about good parenting directly from situations that work well for deaf children are far rarer. This is a curious lack of focus, particularly in the UK context, where studies of parenting disabled children (Beresford, Sloper, Baldwin and Newman, 1996), mainstream parenting education programs (Lloyd, 1999), and the Government's own "Quality Protects" good enough parenting agenda (DoH, 2000) are all promoting a 'what works' framework within which to understand better parenting.

Another significant difficulty in seeking to build a framework for understanding what good parenting might be with deaf children, is that we have little evidence from deaf children, or from the adults they become, of what marks out a satisfying parenting experience for them. Gregory's 1995 follow-up study of 16 to 18 year olds and their families, first studied in 1976, and the narrative work of Steinberg, are rare exceptions (Gregory et al, 1995; Steinberg, 2000). Although not focussing specifically on parenting per se, these accounts of growing up experiences provide rich insights into the daily lives of deaf children and their parents.

The increasing number of D/deaf adults working with deaf children and their families in the UK (Young, Griggs and Sutherland, 2000), is another means by which D/deaf people's experiences of having been parented is beginning to influence the practice of parenting for hearing people (Young, 1997). However, much of the knowledge derived from personal experience that D/deaf people bring to their work with hearing parents remains implicit and unrecorded (Young, 1995).

These significant difficulties surrounding the conceptualising of, and evidencing of, parenting and deaf children, became particularly pertinent in early 2001, when the National Deaf Children's Society (NDCS) in the UK received a large Government grant to develop a "parents' toolkit" for parents of deaf children (*TALK*, 2001). Its purpose was to address the skills, needs and resources required to assist hearing parents in bringing up their deaf children.

As stage one of this work, NDCS commissioned a critical literature review of the published work on parenting and deaf children in relation to hearing parents. The aim of such a review was twofold: firstly, to provide a solid basis for the development of an interviewing instrument to be used with parents, in order to explore their experiences of parenting, and secondly, to provide one of a variety of inputs that would help direct what that toolkit should address, and how it should be conceived. Details of this part of the project are provided in the companion volume: *Parenting and deaf children: Report of the needs assessment study undertaken as part one of the NDCS Parents' Toolkit Development project* (NDCS, 2003).

Some difficulties in the literature reviewing task

Given the conceptual challenges previously outlined when thinking about parenting and deaf children, it became clear that the literature review task was not going to be a simple one. The key problems were:

(i) any core literature set specifically on parenting and deaf children was likely to be very small;

(ii) but nevertheless, a significantly large amount of relevant information does exist, it just exists within research from a very wide and diverse field of subjects;

(iii) consequently, whilst information on parenting and deaf children can be derived from studies that directly address various aspects of it, it is also derived as a consequence, implication, or corollary of studies that might have focussed on something else (eg early interaction);

(iv) some approaches to framing the parenting experience (eg the what works approach), were known to be significantly under-represented in the available literature;

(v) a focus on available knowledge does not necessarily give us a strong sense of what knowledge is missing and needed;

(vi) the boundaries of what will count as literature that is 'relevant' to parenting and what will not, are very fluid.

In addition to these conditions was also the fact that the literature review had to perform a specific function within the wider needs assessment and development project. This condition would also influence both the boundaries of the literature that would be surveyed, and how that literature came to be presented in the final product. Full details of the basis on which decisions were made about which literature to include/exclude are provided in the *Appendix*, along with the search strategy used to identify potentially relevant literature.

In what follows, the literature review will be presented using a four dimensional psycho-social framework that was derived from the literature search process: skills and competence; identity, family characteristics and diversity; roles; and services. The intention in organising the literature in this way is not to be prescriptive. Indeed, as will become clear, boundaries between the different dimensions are rather fluid. However, it is intended as a critical thinking tool to help organise meaningfully what we know and what we do not know about parenting and deaf children in the context of working to develop a useable parenting resource (the toolkit).

Skills and competence – contexts of process

As already discussed, much of the parent guidance literature for parents of deaf children reflects the tension between what we have termed the 'specialing' of parenting and the 'normalising' of parenting deaf children. On one level, this is a simple acknowledgement that there are material conditions, psycho-emotional responses, and social responsibilities associated with parenting a deaf child that are the same as parenting any child (DoH, 2000), and some that are different or realised in a different manner (Ogden, 1984). Indeed, it would be possible to begin to list those skills that are in common with all parenting and those that are in some way different. But on another level, there is something far more important about this 'specialing – normalising' tension in the literature: namely, the discussion of what the consequences are of an over emphasis on one or other of these positions in relation parenting in the context of deaf children.

One of the key issues underpinning the normalisation of the parenting role, and the skills it entails is to combat the sense of inadequacy, de-skillment and lack of parental competence many parents experience when faced both with their child's deafness (Marschark, 1997), and with the paraphernalia of new knowledge, services and service relationships that having a deaf child inevitably entails (Beazley and Moore, 1995; McCracken and Sutherland, 1991; Pearson, 1984). This preservation of parents' sense of their own competence is considered vital if later developmental difficulties for the child

(Greenberg, 1993; Pollard and Rendon, 1999), and difficulties in family functioning (Hintermair, 2000a) are to be avoided. As Pollard and Rendon (1999) remark:

> "It is critical that all parents, hearing or deaf, have a basic attitude of competence and confidence in raising their children. If a parent does not feel competent and confident in parenting - if they feel 'powerless' for whatever reason - the parent-child relationship as well as the child's psychological development and academic achievement is likely to be compromised…Treatment of these families involves rebuilding the parents' sense of competence not by teaching them many special things about raising their child, but through demonstrating that their inherent parenting skills are largely sufficient for promoting their child's healthy development."
> (p.157/158)

Indeed, it could be argued that factors that are found to be important predictors of deaf children's academic success and personal development are ones likely to be associated with parents who have a strong sense of their own competence in their role as a parent of a deaf child. For example, Schlesinger (1992), in a study that followed forty families of deaf children for twenty years, found that the best predictor of literacy achievements in deaf children at third grade level was the "empowerment of the mother". This factor was more important than the degree of the child's hearing loss, the family's socio-economic status, or the educational

methodology used. As Luterman (1999) comments:

"This finding confirms the author's own experience in that if one has a self-confident parent, one will have a well adjusted child who performs well, and [communication] methodology becomes irrelevant… All clinical interventions need to be evaluated in terms of whether or not they enhance the self-esteem of the parents; there is no more powerful intervention."
(p.1049)

Yet despite the demonstrable importance of de-emphasising the extraordinary, difficult, different, or unusual aspects of parenting a deaf child, for the sake of boosting parents' sense of competence, the fact remains that parenting a deaf child *does* inevitably involve the acquisition of skills, knowledge and experiences that differ from those of the majority of parents. In this respect, the fundamental issue is clearly that of communication, and the fact that a deaf child's language acquisition cannot automatically be regarded as a predictable product of early child development (Gallaway and Woll, 1994). Moreover, it becomes something in which parents have a deliberate and self-conscious role to play. Furthermore, this role is one shared with a variety of professionals, part of whose job will be, in some way, to instruct parents in what to do:

"Traditional parent programming involves participation, training, and education…training involves actual step by step guidance from the professional staff to develop parenting skills and facilitate changes in behaviour that will enhance parent-child interactions."
(Somers, 1987, p.74)

Much of the literature on parenting and deaf children does indeed focus on what these special communication skills and abilities might be, how to acquire them and from whom.

The topics are vast and varied: for example, learning how to structure the early linguistic environment in such a way that connects for deaf children objects with the language used about them (Kyle, Woll and Ackerman, 1987); learning particular communication systems, techniques or languages to support the deaf child's language development (Lynas, 1994); the development of facilitative rather than controlling or intrusive interactive styles (Lederberg, 1993; Spencer, 1993); and the exploitation and training of the child's visual and/or auditory attention (Kyle and Sutherland, 1993; Mohay, 2000).

Other common parenting skills also take on a different dimension if communication between parent and child is problematic or incomplete. Issues of discipline, boundary setting, routines, explanation, social conduct and manners, are all ones that in some way require a different approach that is linked *both* to language and to the consequences of not hearing (Gregory 1976; Gregory et al, 1995; Medwid and Weston, 1995; Morgan Redshaw et al, 1990).

For example, the child not being able to hear will mean that parents have to adopt a 'warning of danger strategy' that does not involve shouting at the child from a distance. This is a consequence essentially linked with hearing/not hearing. On the other hand, language rather than hearing is the issue in situations where less than fluent communication between parent and child may mean that the parent can successfully stop the child from doing something (eg throwing his sister's toy across the room), but cannot necessarily explain to the child why that behaviour is not acceptable.

But in thinking about parenting and deaf children, perhaps what is more important is not to focus attention on *what* the particular and special skills might be that parents have to learn, but rather on *how* they are likely to be acquired and executed by parents. The reason for this attention to process rather than definition in relation to skills is fourfold.

First, it is not just that parents are acquiring new skills, knowledge and experiences, but in so doing they are also acquiring different roles (teacher, communicator, advocate etc). We know from parents' own accounts that how these roles are managed, balanced, understood and integrated into daily life is crucial to the parenting experience (Fletcher 1987; Robinson 1987; Shaw, 1985).

Second, the identity and characteristics of both individual parents and families have a pervasive influence on *how* parenting is practised, be it in the approach to new skills (Fewell and Gelb, 1983), adjustment to childhood deafness (Bodner Johnson, 1985; Nash, 1975), or in the values and priorities of pre-existing approaches to parenting (Bailey, 1987; Chambra, Ahmad and Jones, 1998).

Third, the acquisition of new skills, knowledge and experience is for parents a process through which they themselves are learning and growing (Ling-Phillips, 1987; Morgan-Redshaw et al, 1990). As Seideman and Kleine (1995) suggest in relation to parenting children with learning difficulties, the experience is therefore one of "transformed parenting", raising the question of who parents as individuals *become* through this process of transformed parenting, and how they come to terms with a parent identity that is likely to be different from the one they had expected (Luterman, 1999; Vaccari and Marschark, 1997; Voysey, 1975). Fourth, for parents of deaf children, the skills associated with bringing up a deaf child – be they conceived of as the same and/or different from bringing up any child – are experienced at an interface with professional service providers. The nature of the relationship with those services and service providers will have a significant influence on how parents view themselves and their tasks (Beazley and Moore, 1995; Young, 1999), and the range of decisions they make in parenting a deaf child (Elewke and Rhodda, 2000).

In the sections that follow, each of these issues of process will be explored as we turn to the topics of identity, roles and services.

Identity, family characteristics and diversity

It is quite commonly suggested that every deaf child is different and every family situation in which that child will grow up, is bound to be unique (Lutermann, 1999). But a simple acknowledgement of diversity and of the complexity of variables at work within a family does not really take us very far in thinking about parenting and deaf children, unless it is possible in some way to analyse how the diversity of parents impacts on the parenting process.

In other words, what do we know about how the personal characteristics of parents, their social and cultural identities, and the family and community contexts in which child rearing takes place, influence how deaf children are parented? In this respect there are four issues: pre-existing psycho-social and cognitive styles; expectations of the deaf experience; values, priorities and culture; and socio-economic circumstances.

Pre-existing psycho-social and cognitive styles

The first and obvious point to make is that parents and families existed before the deaf child was born. Whether explicitly recognised or not, parents and families will have their own priorities, values, cultural characteristics and 'ways of going about things' that are intrinsic to parents' identities and how families function (Young, 1995). Whilst much of the literature on the early impact of a deaf child on the family tends to focus on the disruption to parenting expectations, normal family patterns and the colossal differences the child will bring

to the family (Harris, 1982; Kampfe,1989; Paget, 1983), these continuous features of parent identities are there also, and exert influence (Fewell and Gelb, 1983).

For example, on a psycho-social level, we know that differences in parents' coping strategies and abilities to deal with stress are correlated with differences in parental adjustment and adjustment to their child's deafness, both early on in the experience of having a deaf child, and at key transition points like adolescence (Calderon and Greenberg, 1993; Mapp and Hudson, 1997). In essence, the more effective, sophisticated and flexible a parent's coping strategies are, then the more likely they are to be successful in adjusting to their child's deafness and dealing with the unfamiliar and stress producing situations it may bring into their parenting experience. These coping strategies are primarily products of parents' *previous* life experiences.

As a result of our own experiences of being parented, family backgrounds, education and social experiences, all of us have developed preferred coping styles, problem-solving abilities and stress modifiers – some of which are more effective than others. It is these that parents will apply to the unfamiliar deaf child context in which they find themselves. In thinking about parenting a deaf children, therefore, attention to maximising the effectiveness of parents' pre-existing coping strategies, and enhancing their repertoire of styles and skills, would have a positive impact on the whole range of challenges they face in rearing a deaf child (Calderon and Greenberg, 1999; Kroth, 1987).

Features of parents' personal characteristics and cognitive styles are also quite regularly found as confounding variables in studies that try to isolate the influence of particular interventions on particular outcomes for parents and children. For example, Hintermair's study (2000a) of the link between, on the one hand, parental competence, and on the other, parents' contact with other parents of deaf children and with deaf adults, produced some difficult to explain results. The finding that parents with the highest appraisal of parenting competence and confidence were the ones that had the most contact with deaf adults could not necessarily be explained by a simple cause and effect relationship.

> *"Relating to hearing-impaired adults for this group of parents means being more content with life, possessing the energy physically and emotionally to meet the challenge bringing up a child, and being able to use strategies for coping with life. However, this does not imply a simple cause-and effect philosophy in the sense of 'Relating to deaf adults will make you content and enable you to master life with a deaf child.' It is just as feasible…that parents who have high-level personal skills, as shown, for example, when they are confronted with a new situation in their lives, tackle it in a more open-minded and sophisticated ways and are more capable of making use of the available intervention programs."* (p.47)

In other words, the characteristics that make some parents more able than others to seek out and use the support of D/deaf adults, which might be regarded as an unfamiliar and particularly challenging option, are precisely the same characteristics that are likely to make some parents more successful than others at using intervention programs anyway.

Similarly, the existence of social support is identified as a key variable in facilitating both parents' adjustment to their deaf child but also in enabling them to be effective parents. But the quality and/or quantity of social support cannot explain in itself why such provision serves to modify stress and enhance parenting for some parents while for others it does not (Bernier, 1990).

Studies that have attempted to unravel the complex relationship between social support and various aspects of parents' experiences of bringing up a deaf child continue to identify aspects of personal characteristics and social resources as significant. For example, Quittner et al (1990) did not find a strong relationship between levels of social support and maternal adjustment to a deaf child, but between *perceptions* of that support and the outcome for the mother. Whilst some factors governing that perception were related to the here and now (eg child related stressors), others were related to features such as the extent to which individuals may be inclined anyway to a more positive or negative appraisal of life events and social situations.

Studies such as these map highly complex interactions between parent characteristics, social circumstances and outcomes that we do not fully understand. The influence of socio-economic circumstances and other on-going life events (eg death in the family) also of course play their part. But on a practical level, what such studies tell us about parenting and deaf children is that in seeking to provide parents with effective 'input' to support them in bringing up their deaf child (eg early intervention, parents' groups, education, skills training etc), we must also pay close attention to effective 'uptake'.

Enhancing parents' pre-existing characteristics and qualities at the level of coping strategies, self confidence, personal appraisal of abilities, risk-taking, problem solving, and so forth, will also enhance their abilities to make the most of whatever support and intervention is available, and also enhance their adjustment to their child's deafness (Bailey, 1987; Calderon and Greenberg, 1999; Kroth, 1987). As Calderon and Greenberg (1993) remark:

> "It is rare for families to receive a systematic assessment of their qualities or characteristics in order to determine the appropriate services for each individual family." (p.28)

This input/uptake relationship as mediated by parent characteristics and family circumstances is one we will return to later in looking at the interface of parenting with services.

Expectations of the deaf experience

It is well recorded that the vast majority of hearing parents have little or no experience of deafness prior to having a deaf child (Gregory, 1976) and are, therefore, constantly engaged in a process of building up new knowledge (Harvey, 1997). However, the situation is slightly more complex that not having knowledge or experience. To use a concept borrowed from Schutz, deafness lies outside parents' "sphere of relevance" (Schutz, 1962). What he meant by this is that for all of us there is a whole complex set of subjects, experiences, people and contexts that have a *meaning* for us, because they in some way affect who we are, how we live, what our priorities and values are, how we perceive our own identity, and how we present ourselves to the world.

However, deafness comes to most families as an "imposed set of relevancies" (Voysey, 1975), thus engaging parents in an ongoing process of trying to understand what the deaf experience is and what meaning deafness is to have in their lives and in the life of the family (Young, 1999).

This notion of how parents build up their meaning of the deaf experience is significant to a discussion on parenting, because we know that the assumptions parents hold about what it is to be deaf affect their decision-making concerning their deaf child.

"Early in a child's life, a parent will attribute meaning to being 'deaf'. That interpretation will have an impact on parental feelings and interaction with the child. If a parent views his child as unique rather than flawed, the child will develop a more healthy view of himself."
(Medwid and Weston, 1995, p.11)

"Your [parents'] choices will be greatly influenced by your knowledge of and your attitudes towards deafness, deaf people, and the current state of deaf education."
(Schwartz, 1996, p.89)

This effect is most obviously seen in relation to communication (Nash, 1975). To take some broad examples, if for a parent deafness carries a meaning of personal tragedy, likely social exclusion and isolation, then an approach to communication that seems to maximise a child's ability to speak and hear as near 'normal' as possible will make sense (Schwartz, 1996). On the other hand, if for a parent the meaning of deafness is that of a particular linguistic and cultural experience of the world that is apart from, but still connected with, the hearing world around, then a sign bilingual approach to communication is likely to seem to make sense (Knight and Swanick, 1999).

Clearly in reality these connections are not going to be as stark as they have just been presented, and for parents building up a picture of deaf people's (and their particular deaf children's) experience of the world, it can be a puzzling, and in some

cases, painful process of growth and realisation. As Erting (1992) remarks:

"[Parents have] an awesome and unusual challenge of raising a child who experiences the world in a way profoundly different from their own experience of the world."
(Erting, 1992, p.36)

Nonetheless, the connection between assumptions about deafness/the deaf experience, and choices made in parenting a deaf child remains a very powerful one. At the level of personal adjustment, we know that the model(s) of deafness to which parents are exposed (be they medical, social, or cultural) influence that adjustment. Beazley and Moore (1995) for example, go as far as suggesting that professionals' implicit assumptions that deafness is a tragedy/medical emergency, and that deaf children are in some sense in need of repair/habilitation, are socially constructed reactions, that serve to *engender* a grief response in parents, rather than that grief response being a natural consequence of the child's deafness.

An investigation of parents' responses to exposure to Deaf adults and a strongly cultural-linguistic model of deafness in the early years, reveals how parents become aware of their own 'hearingness' (Young, 1999), as much as they become aware of their child's deafness and the resultant tensions and contradictions that can create in daily life (Young, 1999). As Henderson and Hendershott (1991) remark about hearing families that have

chosen to use ASL at home, there is a difference between families which, in taking on the notion of becoming a bicultural bilingual family, reconstruct themselves as a 'Deaf *and* hearing' family, and those families which remain essentially hearing families with a deaf child.

So in thinking about parenting in the deaf context, a central issue is what exactly that deaf context is for parents, and what influences and defines the expectations, assumptions and understanding of the deaf experience they hold. It is important because those expectations affect key decisions parents will make in relation to how they treat their deaf child, the aspirations they hold for him/her, and how the family functions. This issue of how expectations and understandings of the deaf experience are formed and revised is an underpinning concept to much of the discussion to follow.

Values and culture

Much of the previous discussion is also a discussion about values and their influence on parenting, if by 'values' we mean: "standards by which a person directs his [sic] actions and defines, interprets and judges all social phenomena" (Aponte, 1985, cited Bailey, 1987, p.62). But in the literature concerning deaf children, there are in addition two particular issues that recur concerning family and social values: the transmission of family/cultural values and social norms; and the relationship between personal/family values and the

experience of bringing up a deaf child, rather than a hearing child.

As Gregory (1991) has remarked, parents of deaf children, in the same way as all parents, are "vitally interested" in the transmission of their own family values and culture. This is not necessary an explicit process, but one that forms a natural part of child rearing, both in terms of passing on a social and cultural identity, and also in terms of the acceptance of parental responsibility to 'teach' the norms of social and cultural behaviour in whatever society the child is being reared. The problem in the deaf context is that this process usually gets interrupted in some way, though the reasons for a more problematic transmission of family values or social norms are rather varied.

On one level, there is the issue of communication. If parents and children do not share a fluent and elaborated means of mutual communication, then it becomes difficult to share or explain the world in which the child finds themselves growing up. The problems many parents face in explaining to their deaf child why they cannot do something, rather than simply preventing them from doing it, is an oft-cited example (Medwid and Weston, 1995). Indeed, many deaf children's experience of a world without connections between actions and explanations is one of a range of factors that can contribute to the high rate of emotional and behavioural disorders experienced by deaf children (Hindley et al, 1994).

From parents' perspective, less than optimal communication can reduce the opportunities to share experiences, reinforce attitudes and ways of understanding the world that they would want to pass on to their children, and of just enjoying building up a repertoire of shared understandings of each other and the family. The following quote from a parent's account is illustrative:

> "I was looking forward to when she come home from school and she could tell me what she's done and that today and call me mummy and come out with some funny things like they always do when they're around three, four, five. And it was certain things that I was going to miss, but I know I never had it, but I was going to miss them anyway." (Hearing parent, cited in Young, 1995, p.190)

The other major way in which communication issues interrupt the transmission of family values and social/cultural norms is through the reduced opportunities for incidental learning and 'overhearing'. With hearing children, it is taken for granted that much of their social learning about manners, moral values, responsibility, and how to behave in a variety social situations, is picked up through exposure to how others behave and what they say both within the family and peer groups. But as David Wright (1969) wrote of his own experience of growing up deaf, it was one of growing up within a "whole incommunicable and uncommunicating universe" where, therefore, the opportunities for effortlessly picking up such vital social developmental information were significantly reduced. Parents of deaf children find themselves instead in a position of having *deliberately* to teach, explain and reinforce norms of social behaviour that they would not usually expect to in the same way a part of their parenting experience. As Ogden (1984) describes:

> "Many patterns that normal-hearing people take for granted and that normal-hearing children learn by imitation must be identified and painstakingly explained to the hearing impaired child." (p.37)

However, beyond the issues of less than optimal familial communication, there is also the issue of how intervention and particular approaches to bringing up a deaf child can challenge the transmission of values that a family may consider essential. A common criticism of bilingual/bicultural approaches to early intervention, for example, is that by constructing the deaf child as a proto member of another culture (ie Deaf culture), and encouraging hearing parents to bring up their deaf child with the language and mores of that culture, one creates the fear in parents of "losing" their child to that culture (Gregory, 1991). Indeed, for some hearing parents, contact with Deaf culture and sign language represents a threat to their best effort to "normalise" their deaf child's up-bringing, when normal is taken to mean hearing, speaking and being integrated through those means into the hearing society (Gregory, 1993).

Clearly, it could be argued that it is deafness that parents fear, rather than Deaf culture, and that the many parents who do embrace a bicultural approach to bringing up their deaf child experience a wider variety of possibilities for their children's development, and for their parenting roles (Knight and Swanwick, 1999). But the basic point remains that deafness, and the approaches to intervention in the family that it spawns, have the potential to challenge parents' own sense of continuity between themselves and their child (Young, 1999).

This notion of threat to continuity between parent and child is seen starkly in research with hearing families and deaf children from minority ethnic backgrounds. As Ahmad et al (2000) famously quote from their studies with Asian families in the UK: "I sent my child to school and he came back an Englishman….". In other words, whilst family intervention and deaf education may be tailored to the needs of the deaf child as 'deaf', they may not be tailored to the cultural identity of the child and his/her family values and traditions (Parasnis, 1997). It used to the be the case, for example, that Asian deaf children in some parts of the UK would be exposed to spoken English and/or BSL, but not their home spoken language, only serving to intensify the potential home communication difficulties, and to alienate the child from their own cultural heritage (Chambra et al, 1998).

Similarly, writing about the transmission of social norms and deaf children in some Black communities in the USA, Fishgrund et al (1987) remark:

> "Black communities often evolve a network of significant adults who firmly correct undesirable behaviour in neighbourhood children and report it to the parent. The significant feature of this system is that it appears to operate externally to the child, with the child developing an external locus of control. In most school situations, however, adults act as if the locus of social control exists within the child. They do not behave in ways consistent with the Black child's expectations of how adults should act toward them in situations requiring the enforcement of social controls." (Fischgrund et al 1987, p.62)

In short, in thinking about parenting in the deaf context, the transmission of family, social, and cultural values and norms of behaviour is a key parenting task, and one that is rendered problematic, both by the impact of deafness on the family, and by the relationship between family identity and service responses. These inter-related features are not easy to tease out, but from the parents' perspective, create day to day hassles and challenges in parenting a deaf child. Perhaps if we understood more about the diversity of cultural responses to deafness in the family (eg Steinberg et al, 1997) professionals and parents alike would be better equipped to ameliorate such challenges.

Socio-economic features

Although it might seem rather obvious to state, parents of deaf children are a highly diverse group. Deafness does not discriminate between class, economic status, culture, or lifestyle. And yet, in writing about and researching families with deaf children, the impact of this diversity is often lost. Features of common experience between families may take precedence, or it may be particularly difficult to account for the effects of differences in home background or parent identity on the developing deaf child. Some of these issues have been discussed already in previous sections when looking at psychosocial/cognitive styles, and values and culture. However, in what follows we are going to be focussing on more socio-economic factors related to diversity such as material conditions, poverty, housing, and the effects of class and social expectations on parenting a deaf child. As will become clear, we know remarkably little about these issues in the context of parenting and deafness.

Whilst there has been a considerable amount of research in recent years concerning families, financial/social conditions, and disabled children in general, there has been almost nothing focussing specifically on families with deaf children. This omission is perhaps not surprising, considering the low incidence of permanent childhood deafness in the general population (Davis, 1995) and the relatively small size of the UK. Finding viable enough samples across different social strata prepared to participate in studies is a difficult task. Nonetheless, from the more general studies of families with disabled children (many of which included within their study families with deaf children), several important characteristics have become clear (Beresford, 1995; JRF, 2000).

Firstly, a large number of parents of disabled children experience significant poverty. In the UK context, it has been found that parents of disabled children face three times the costs of bringing up a child than parents of non-disabled children, and that the average cost of bringing up a disabled child is considerably more than even the maximum benefit levels would provide (Dobson and Middleton, 1998).

This financial situation is not helped by the fact that many parents of disabled children experience significantly diminished employment opportunities because of their roles as carers and find it hard to combine paid employment with caring because of inflexible employment conditions (Kagan, Lewis and Heaton, 1998). In addition, it has recently been established that around half of families with disabled children are living in unsuitable housing (Oldman and Beresford, 1998). Whilst this finding might seem more immediately relevant for parents of children with physical disabilities, the study's definition of 'unsuitable' also encompassed the wider community context of the housing and local environment – factors often relevant

to families with deaf children. Also between 30 and 40% of deaf children have disabilities/complex needs some of which could encompass mobility issues and high dependency physical care (McCracken, 1998).

In other words, it is quite clear from these studies that the stress and challenge of parenting a disabled child is considerably compounded by such socio-economic factors (JRF, 2000), and that conditions of material and financial hardship are not unusual for families with disabled children in this country. Whilst these studies are of disabled children in general, the trends they identify are of relevance to parents of deaf children and deaf children with disabilities, particularly in light of the evidence of the greater stress experienced by parents of deaf children with additional needs (Hintermair, 2000b).

To turn back now specifically to parenting and deaf children, there is one particular issue where factors such as parents' employment status, financial circumstances and education history have become a focus of interest. This is in response to the demands of early intervention and the development of deaf children's language and communication. There is a long history of the degree of parents' commitment to working with their deaf child on communication being regarded as a predictor of the child's successful development (Ewing and Ewing, 1964; van Uden 1977). Whether that 'working' is defined as: sustained involvement in parent guidance programmes; learning sign language;

following a regime of listening training/speech development at home; attendance at specialised playgroups; or following the advice of any number of professionals that might visit the home, any factor affecting a parent's ability to be involved and to carry out the required roles are of importance.

However, as some writers have argued, perhaps we are looking at the issue the wrong way round, and the problem lies with approaches to early intervention that *presume* certain social roles of parents that they then have to fit into in order for the intervention to be effective:

> *"The professionals and agencies with whom they deal also have a set of attitudes and beliefs in which they place the parent, and then develop a set of instructional setting characteristics to move that parent toward the goals the professionals take."* (Gordon, 1979, p.24)

Programmes of intervention and support may be designed on the assumption that parents have the time, financial security and material resources to be able to fit in to their demands and timetables (Robinson, 1979). But as Somers (1987) argues, this is often a false and divisive assumption:

> *" Though widely recognised as essential to their children's early intervention efforts, parents who have their own special needs are often ignored. For example, the specific needs of dual career, single parents, low-income and minority families*

require special consideration when parent-education programs are designed…

…Unfortunately, working parents do not often arrive home in the best condition in which to work with their hearing impaired children in an intensive, structured way…programs must be planned and fit the demanding lifestyle of a growing number of working families."
(p.69)

Indeed, there is plenty of evidence to suggest that many parents (predominantly mothers), find that they have been forced to make difficult choices not to pursue particular careers, qualifications, or to work at all, in order to meet the needs of their deaf child in the family (Beazley and Moore, 1995; Gregory et al, 1995; Ling-Phillips, 1987). The degree to which these choices could have been different if programs and intervention were more flexibly designed is unknown. Also largely invisible in the literature are those parents for whom lifestyle choices in the wake of having a deaf child are far more severely restricted: for example, parents who for financial reasons have no choice but to work; or parents of large families existing under multiple sources of stress and social deprivation where involvement in early intervention may not be their first priority.

The social profile of parents in relation to their educational background has also been raised as an issue of importance. As we will consider in more detail later,

one of the primary experiences of parenting a deaf child is contact with a very wide variety of professional groups, all of which, as Kroth (1987) remarks, "speak a different language". Some parents from poorly educated and/or working class backgrounds will feel ill-equipped to understand and interact with largely middle class, well-educated professionals, and vice versa (Bailey, 1987). As Fischgrund et al (1987) remark:

"There is no normal response to loss, thus one should not be expected. For the poor, poorly educated, or non-English speaking family, information presented by a professional during this time may be misunderstood or misconstrued, possibly becoming the basis for responses that are misinterpreted by the professional."
(p.64)

Clearly, establishing effective two-way communication between parents and professionals in circumstances of social and educational difference is a vital priority if parents are to feel confident enough to ask questions, process information and engage with whatever intervention will support their child's development (Dale, 1996). Failure by professionals to tune into values, priorities and assumptions about parenting that might not be their own, will impair the support of children and parents alike (Bailey, 1987; Gordon, 1979).

Summary

In looking from different perspectives at identity, family characteristics and diversity, we have sought in this section to unpack the simple assertion that all families are different and to try and examine what we know about the impact of that diversity on parenting a deaf child. Not surprisingly, the picture is a complex one, with factors pre-dating the birth of a deaf child being as significant as the new experiences that deaf child brings to the family. It has become clear that only by actively addressing the identity/identities of families within their social/cultural contexts will we understand their experience of parenting, their uptake of support and intervention, what differentiates success from struggle, and the processes by which their roles as parents of deaf children develop. As has been suggested, to ignore this highly individualised context is to miss something essential in any attempt to influence parenting:

> "Parent child-rearing techniques are still embedded in an abiding and persistent socio-cultural context, and there is no evidence that they are cosily shaped by expert opinion or educational literature."
> (Clarke and Stewart (1981) in Fewell and Gelb, 1983, p.193)

Roles

As the range of previous discussions has consistently demonstrated, one of the fundamental experiences of parenting a deaf child is that of fulfilling multiple roles. Parents themselves talk about becoming educators, advocates, interpreters, campaigners, experts, and clients (Beazley and Moore, 1995; Gregory et al, 1995; Moores, 1987; Morgan Redshaw et al, 1990) as well as mum and dad. As one parent has remarked:

> *"Because of the deafness we've organised things that we'd never have done, we've been to places we'd never have gone to, we've done things we'd never have done."*
> (Gregory et al, 1995, p.223)

Clearly, it could be argued that any parents of any child find themselves fulfilling a number of different roles within that relationship, so why should it be particularly different or special for a parent of a deaf child? Part of that question has already been answered in previous discussions of parents' roles in the development of language and communication and the way in which less than optimal family communication renders many of the taken for granted aspects of parenting more problematic.

In addition, the literature points to two other issues which will be discussed in this section: firstly, adolescence and the parenting role; and secondly, what we know about fathers' roles in the context of deaf children. The related issues of other professionals or groups playing significant parenting roles in the lives of deaf children will be covered in the following section on services.

Adolescence and the parenting role

Several researchers have demonstrated how adolescence can be a time of particular challenge, and in some instances crisis for parents of deaf children. Two specific parenting dynamics underlie this experience beyond those more routinely encountered by many parents of hearing children.

The first is the apparent mismatch of expectation and reality (Morgan Redshaw et al, 1990). As issues of independence and preparing their deaf child for adult life become more pressing, many parents experience a disparity between what they had hoped for, or were told was possible for their deaf child, and what the reality shapes up to be (Moores, 1987). This disparity might be to do with communication and language development. For example, parents who had presumed their children would be fluent users for spoken language, discover they are not (Moores, 1978). Parents who had presumed that society would be accepting of the skills and abilities of their deaf children, find that barriers to employment, and significant social prejudice remain (Gregory et al, 1995).

Secondly, many parents talk in different ways about how the emerging young deaf person challenges their concepts of normalcy (Leigh, 1987). In other words, the image that parents had of a young deaf person, or that promoted by professionals is not what they see first

hand. This issue is not about young deaf people in some way failing to live up to expectations, but rather discovering alternative expectations and possibilities of a Deaf identity that their parents may not have been aware of or have rejected at an earlier stage.

In this respect, adolescence and young adulthood is the time that some deaf people discover sign language, have friends who use sign language, and choose to mix within the Deaf community/Deaf social circles. These processes involve them in taking on an identity that their parents may be ill equipped to understand or respond to. As Gregory et al's (1995) follow up study of young deaf people and their parents demonstrates, many parents who initially had rejected the notion of signing with their children begin to learn to sign, not only to be able to chat to their deaf children's friends, but also to understand something of the deaf young person their son or daughter is becoming.

These experiences provoked by the deaf child's developmental transitions into adulthood can have devastating consequences for parents. Many talk about a resurgence of feelings of grief and loss as the full extent of the ways in which their deaf child will not be like hearing adults becomes apparent (Morgan Redshaw et al, 1990). Some experience anger, frustration and a sense of betrayal by professional services, which they see as ill-equipping them or misleading them about the young adults their child would become (Moores, 1987).

For others, there are significant feelings of guilt about what, in looking back, they could have done differently to support their deaf child to become the young D/deaf person they now want to be (Gregory et al, 1995).

"It is at this time [adolescence] that many parents see their hopes smashed, their dreams of 'normalcy' crushed…Because they were not helped to work through the conflict when the child was young, the final realisation unleashes a tide of frustrations, resentment and hostility which is vented on the system of professionals that has misguided them and failed to prepare them for reality."
(Moores, 1978, p.101)

"Nevertheless, the inability to cure the child or to prepare the child fully for life was painful and frustrating for the mothers. They saw the child's hearing impairment as a burden. Although these negative feelings and emotions diminished as the child grew older, they continued to resurface."
(Morgan Redshaw et al, 1990, p.296)

But the picture parents paint of their experiences through their child's adolescence/young adulthood is by no means entirely negative. In fact, it reveals some interesting characteristics and changes in the parenting role. For some parents, it is a time of acknowledging their increasing expertise and confidence as parents of deaf children. Whereas in the early years, everything was new, and the explosion of specialist information created

problems of assimilation and understanding (Leigh, 1987), as the child grows up, some parents find they are in a highly informed position (Morgan Redshaw et al, 1990), that enables them to take a more active and satisfying part in decision-making concerning their children:

> "At secondary level more parents were selecting their child's school and also the bases upon which their choices were being made had changed. Parents know more about their child, more about deafness and more about the educational system as it existed for deaf children."
> (Gregory et al, 1995, p.74/5)

Indeed, it is not uncommon for parents to report that they have more expertise and understanding than many of the professionals that their children, as increasingly independent young people, are required to encounter eg careers advisors, interviewers for jobs, general practitioners, bank managers etc (Gregory, et al, 1995). Consequently, a commonly reported experience is of parents assuming new roles and old roles diminishing (Morgan Redshaw et al, 1990) as they support their children through these new interfaces with hearing society. Typically, parents might find their roles as advocates taking precedence over roles as teachers, or roles as interpreters taking precedence over roles as carers. These shifts are often subtle and largely dependent on the individual circumstances of child and family. But nonetheless, many parents report an experience of an 'extended' parenting

role, if by 'extended', we mean parents fulfilling roles for their deaf children that they would not normally expect to do for hearing children of the same age:

> "It has emerged throughout this book that many parents were more involved in the lives of their sons and daughters than they would have been had they been hearing. Support was provided in finding work, job interviews and other interactions with the hearing worlds including visits to doctors. Parents provided guidance in financial matters…They might also be involved in the social life of their son or daughter through assistance with telephone conversations or passing on messages. For a small minority, the parents were involved in most aspects of day to day life."
> (Gregory et al, 1995)

Although, as the above discussions have demonstrated, there are a small number of interesting research studies of parents of deaf adolescents/young adults, we still have very little understanding about how parents come to terms with a young deaf person rather than a deaf child, and the support that they require through this process. It could be argued that t new balance of roles involved in parenting a deaf adolescent/ young person are less a product of the child's age and changing circumstances, and more to do with society's failure to meet the needs of young deaf people by, for example, providing interpreters, better deaf awareness of employers, access to communication technology etc

One thing is for sure, however: many parents of young deaf people have clearly built up incredible expertise, and how service providers could learn from it and use it remains an important challenge.

Fathers and fathers' roles

There is always a certain ambiguity in writing about *parents* of deaf children, because in reality very little is known about fathers of deaf children (Lamb, 1983), and most of what goes by the term 'parents' is often based on information from or about mothers. Traditionally in UK and US society, it is largely mothers who engage with early intervention and remain the primary carers of their deaf children. This is not a universal situation of course, but exceptions are often a product of social engineering or the particular conditions of particular programmes.

One influential early intervention programme for deaf children in the Netherlands, for example, insists that both fathers and mothers must attend parents' groups as a condition of acceptance of the child into the programme (van der Lem, 1994). In Sweden, for example, fathers as well as mothers are entitled to paid leave from their employment to follow language courses/early intervention programmes to support their deaf child – and many fathers take up this possibility (Magnusson and Hergils, 1999). However, in general we know little about the impact of a deaf child on fathers and the roles fathers play within the families of deaf children.

The limited information available is largely based on comparisons *between* mothers and fathers on a variety of measures rather than any exploration in fathers' own terms of the experience itself. [The autobiographical account by Thomas Spradley, (1985) is a rare exception.] Similarities between mothers' and fathers' responses have been found in emotional responses to the diagnosis itself, where the gender of the parent was not a source of significant difference in response (Brand and Coetzer, 1994). However, this result does not take into consideration any differences between parents, through the period of suspicion of deafness prior to diagnosis. Before the introduction of universal new-born hearing screening, this period could be many months, or even years, and is a time of considerable stress and disturbance, as reported routinely by mothers (Gregory, 1976). Interestingly, in a qualitative study of matched pairs of mothers and fathers whose newborns were being routinely screened for deafness, no significant differences in levels of anxiety were found between parents during this process (Magunusson and Hergils, 1999).

However, we currently have no information on similarities and differences of response between mothers and fathers whose children are identified as deaf following newborn hearing screening. It is to be hoped that the study of parents of 'true cases' to take place as part of the national evaluation of Newborn Hearing Screening Programme in the UK (Young, Tattersall et al, forthcoming), will begin to provide some data on this matter.

With regard to stress and support, in a study of 30 couples with deaf children, higher mean stress levels have been found for mothers in comparison with fathers (Brand and Coetzer, 1994). Mothers also reported having less emotional support from their spouses than fathers did (Brand and Coetzer, 1994, p.1365). It has also been suggested that fathers in general have poorer adaptation to their child's deafness, because they are more apt to deny the need to digest the implications of deafness for their child and less likely to develop coping strategies that are appropriate (Leigh, 1987).

Certainly, personal accounts from parents, such as that by Robinson (1987), do highlight differences in coping strategies and adjustments by mothers and fathers. But once again, without more data it is not possible to discern how much of such biographically reported differences are to do with gender and role, and how much to do with particular personalities.

One interesting area of difference that does recur in the literature concerns communication at home. As already discussed, it is predominantly mothers who have most contact with professional service providers and are generally most involved in early intervention programmes with their children. It is, therefore, not uncommon to discover that mothers are better communicators with their deaf children, both initially and as the child grows up (Gregory et al, 1995) – in some cases, playing an interpreting role

between child and father. It is also not unusual for some deaf children to be able to better understand one parent than the other, with fathers with moustaches or beards being notoriously difficult to lipread (Sutherland, 1995).

Even if the dislocation of communication between parents and children is not so extreme, there certainly is evidence to suggest the pivotal nature of mothers' role and their influence on fathers' communication in the home. In a study of 192 deaf adolescents by Kluwin and Gaustadt (1991), they found that the strongest predictor of fathers' mode of communication with their child was mothers' mode of communication with the child, over and above the level of the child's hearing loss, or indeed, their child's usual communication/language used at school.

In summary, we know very little about fathers of deaf children other than that their experience seems to be different from mothers, although qualitatively we do not understand why. Also, as the role of fathers and fatherhood changes in modern societies, it is to be expected that the impact of a deaf child on fathers will also change depending on the social construction of their family roles. In this respect, variations in role expectation and the duty of fathers in different cultures, is also of importance and little discussed (Steinberg et al, 1997).

Summary

In conclusion, parenting in the context of deaf children involves parents playing multiple roles. Whilst this is not an usual experience of parenting per se, in the case of deaf children these roles are to a large extent circumscribed by the needs of the deaf child, and by society's, in some cases inadequate, response to those needs. Although we know that parents often play extended roles in their children's lives, we have little information about how they cope with that experience. Although we know that the emphasis on certain roles changes as the child grows and their interaction with hearing society changes, we know little about how those changes are negotiated between parent and child. Our knowledge of fathers' contributions to the developing deaf child remains very sketchy and cultural variations in the impact of having a deaf child on fathers and their family roles remains largely unexplored.

Services

An underlying theme running through much of what has been already discussed is that parenting a deaf child happens at an interface with service provision. From earliest suspicions, through diagnosis, early intervention, education and the transition to adulthood, service providers are involved in the lives of deaf children and their families. In common with parents of children with disabilities and chronic illnesses, parents of deaf children find themselves in relationships with a host of professional groups that they would, in most cases, never have usually considered relevant to their lives (Dale, 1996; Kroth, 1987). Teachers of the deaf, social workers, audiologists, psychologists and so forth are not just available, but in the majority of cases become obligatory, and integral to how parents raise their deaf child (Gregory 1991; RNID, 2001).

These circumstances raise two important issues in relation to parenting a deaf child: firstly, what the nature and consequences are of parent/professional power relations, and secondly, is parenting a deaf child is a shared experience, and if so, who are the other 'parents', and what are their roles? In what follows, these issues will be explored in turn with reference particularly to the service development context in the UK.

Parent/professional power relations

As we know, the vast majority of parents of deaf children will have no previous experience or knowledge of deafness and deaf children. One of the first and enduring experiences for many parents, therefore, is the search for and acquisition of the knowledge and information they need to support them in that task and in making sense of the experience (Knight and Swanwick, 1999; Marschark, 1997). In the early years, this process occurs simultaneously with that of the psychological and emotional adjustment parents experience in coming to terms with the fact their son or daughter is deaf (Lutterman and Kurtzer-White, 1999). On the other hand, there is a vast array of professionals whom society legitimates as appropriate experts to provide that knowledge and information and to assist with that process of adjustment (Gregory, 1991). Consequently, this relationship between parent and professional is, at least in the beginning, one of considerable power imbalance (Beazley and Moore, 1995). Therefore, how the relationship is constructed and developed becomes a crucial focus of interest (Mertens et al, 2000), if parents are to emerge as knowledgeable, competent, and confident in their parenting – factors we have already established as crucial to their own wellbeing and the child's optimum development.

From accounts both by parents and in reflections by professionals themselves, provision and uptake of information emerges as a critical marker of parent/professional power relations, particularly in the early years. Several recent studies in the UK continue to show that many parents feel that they have received partial or biased information from professionals, particularly with regard to the range of communication choices available to them and their families (Beazley and More, 1995; Chambra et al, 1998; Elewke and Rhodda, 2000; Gregory et al, 1995; Gregory et al, 2001).

Parents report, for example, that they only found out later that there were other alternatives that they had either not been told about, or told about in an impartial manner. They describe experiences of realising that they did not know what they did not know and thus that they had made crucial choices about how to bring up their deaf child without realising the full range of options available to them – be it about language, education or social development.

> *"People such as parents have information withheld from them for 'political reasons'."*
> (Parent in Gregory et al, 2001, p.67)

There are a range of reasons why these experiences happen. Certainly one area of concern is that of attitudes and values (Bailey 1987; Dale 1996). The expert status that a professional is given and their own strongly held beliefs, particularly about the right method or approach to deaf child language development, can cause them to be selective about the information they pass on to parents or the approaches they promote. To be fair, sometimes this selectivity is also a result of organisational structures rather than simply personal bias. For example, it remains the case in the UK that not all LEAs (local education authorities), either officially or unofficially, promote all approaches to language development, nor have the funds for the support structure required for the full range of communication choices available to all parents (Powers et al, 1999; Gregory et al, 2001).

Nonetheless, from parents' perspective the result can be feelings of anger, frustration and betrayal once they discover that there were choices available they were not aware of (Elewke and Rhodda,2000; Gregory et al, 1995).

There is also a concern that parents' experience of feeling they do not have all the information or have been given all the options, is a result of mismatches between the values and priorities of parents and those of professionals (Bailey, 1987). As previously noted, if we define values as: "standards by which a person direct his (sic) actions and defines, interprets and judges all social phenomena" (Bailey, 1987, p.61), then a failure by professionals to understand the particular and diverse values of the range of parents they meet, and their failure to communicate clearly those values that as professionals they espouse and promote, can result not just in a communication breakdown, but also in a failure to effectively meet the needs of families.

Of course, the other side of the coin is the uptake by parents of information. The above discussion has rather assumed that parents are passive recipients of information and dependent on professionals rather than active seekers and constructors of knowledge, able to question and use professionals for their own ends. Thoughts such as these are certainly increasingly leading commentators to think about the empowerment of parents and the development of the skills they need to "use" professionals to get the information and services they want (Gregory et al, 2001; Medwid and Weston, 1995).

For example, from a recent study of families of Asian deaf children in the UK, in which parents and professionals were both interviewed, one of the important themes to emerge was that professionals wanted parents to be more assertive about their requirements, but that parents felt powerless to know how to ask and what to do:

"Practitioners felt that parents needed to be more assertive in their dealings with professionals if they wished to obtain the information they wanted…"

"Many parents felt that even when given an opportunity to ask for information they did not always know what to ask. This made parents reliant on professionals for all relevant information and supported the belief that 'professionals know what we want'." (Chambra, Ahmad and Jones, 1998, p.65)

Some parent groups themselves are beginning to look at this issue of how can they obtain the skills they need to cope with and influence the professionals and services that become a part of their everyday lives (de Georges, 2000). Skills in questioning the information they are given, stemming the flow of information if there is too much of it, in being assertive enough to ask professionals to suspend visits, or to seek another view, are all examples of skills that do not necessarily come naturally to parents of deaf children (Medwid and Weston, 1995). As recent research into parents' and professionals' perspectives on good practice in deaf education in the UK has demonstrated:

"…the importance of empowering parents was seen as one of the major factors in allowing deaf children to achieve their potential, mentioned by 20% of respondents. 9% saw the failure to empower parents as an obstacle to deaf children achieving their potential." (Gregory et al, 2001, p.66)

Also, as we have discussed earlier, differences in culture, language, life experience, class and personality between professionals and parents can all make such assertiveness more problematic:

"…some parents may not feel confident in their ability to act as equal partners with professionals and will need encouragement to contribute to the exchange of information about their child and discussions about available options." (RNID, 2001, p.10)

In professional literature too, there is increasing discussion about how to avoid a cycle of dependency by parents on professionals (Bailey 1987; Leigh, 1987; Luterman 1999). As has been remarked:

"…we do a disservice to families by attempting to meet their every need. A primary goal of early intervention should be to 'empower' parents to advocate effectively, make decisions and solve problems for themselves."
(Bailey, 1987, p.63)

Consequently, there are discussions, both in the deaf-related and more general disability literature of new models of partnership (Dale, 1996; Kroth, 1987); approaches to utilising the pre-existing strengths of parents (Somers, 1987); how to tune in to the values and priorities of families (Bailey, 1987); how to equalise power relationships between professional and parents (Ling-Phillips, 1987); making professional language accessible (Kroth, 1987); understanding how parents *prefer* to use information (Mitchell and Sloper, 2000); and so forth. The impetus behind all of these discussions is on how to maximise the uptake of professional services by parents, so that they are meaningful and targeted in a way that make sense to parents on their own terms, and from within their own unique strengths:

"Families are often more resilient than they are given credit for. A sensitive professional will identify their strengths both to help them realise their ability to cope with a child's handicap and to

establish a partnership with them."
(Kroth, 1987, p.8)

The other key movement currently in the UK context relevant to parent/professional power relationships, is the increasingly acknowledged role of parents as expert consultants both to other parents and to service providers. The central place of parents as resources for other parents has long being acknowledged by organisations such as NDCS (www.ndcs.org.uk) and the American Deaf Children's Society. However, parents' expertise is now becoming more institutionally acknowledged and embedded. The recent national standards for paediatric audiology (NDCS, 2000) formalised the existence of 'Audiology Working Groups' in each area. In essence, these are a multi-disciplinary forum in order to better co-ordinate and plan services to deaf children and their families. Their constitution requires at least one parent to be a member. As has been stated:

"Parents have a right to expect professionals to acknowledge their experience as parents, and to share information. Parents must be involved in the decision making process."
(NDCS, 2000, p.4)

Within the wider fields of parent education and support, the emphasis has also strongly shifted away from professionals as experts supporting parents and to parents as experts supporting each other:

"In recent years there has been focus on involving parents in work that emphasises the normality of parenting,

drawing on the commonality of the parenting experience, utilising each others' skills, and consequently being less reliant on the 'expertise' of professional agencies."
(Lloyd, 1999, p.5)

In summary, significant decisions that parents have to make about the lives of their deaf children and how they as family wish to live, are mediated through their relationship with professionals and the information, knowledge, advice and experience they provide. Therefore, the characteristics of the power relationship between parents and professionals, how it is negotiated, how parents are empowered in that relationship, and how they go on to empower others are crucial issues. Our understanding of the experience of parenting a deaf child must take into account the experience of the parent/ professional relationship but, as parents themselves testify, cannot be defined by it.

Are there other "parents" of deaf children?

To some extent, all children have a variety of parenting experiences and influences from other people besides their own parents. Teachers, siblings, grandparents and particularly inspiring non-familial adults often play parenting roles. In many respects deaf children's experience is no different except for the added factor of communication. Those who are able to communicate well are likely to be more

significant and salient for deaf children. As has been remarked, deaf children grow up in "typically atypical" language environments (Hointing and Loncke, 1990) where the quality of communication and mode of communication from the range of family and non-family adults they meet is highly variable and not necessarily consistent (Mounty 1989).

However, over and above this issue of variable communication, there is another key factor for deaf children with regard to the parenting roles that others might play in their lives. That factor is related to sign language and the Deaf community.

Given that over 90% of deaf children are born to hearing parents, then the 'natural' intergenerational transmission of sign language from parent to child is not common (Johnson et al, 1989). Also the enculturation and socialisation of deaf children into Deaf culture – its norms, traditions and identity – is not something that usually occurs as a result of happening to grow up in family that shares that culture (Jones, 1994; Sutherland, 1994). For many hearing parents these peculiar circumstances are of little relevance because they do not wish to bring up their deaf child with sign language nor see Deaf culture as particularly relevant to their own circumstances. However, for the significant proportion of parents who seek to bring up their child bilingually and biculturally, these circumstances are very important (Knight and Swanwick, 1999).

For a child to acquire sign language as first and fluent language (in addition to whatever the spoken/written language of the home might be) then they need to be exposed to fluent models of that language. For a child to become socialised into Deaf culture as well as into their own family's culture, then they need significant and sustained contact with that culture. Many of the bilingual/bicultural early intervention programs world wide are set up precisely to provide these opportunities, exposing both parents and children to Deaf adults, sign language and the Deaf community (Kyle and Sutherland, 1993; Mohay, 2000; Svartholm 1993; van der Lem, 1994).

However, these circumstances are not necessarily comfortable for parents (Young, 1999). Even if parents do attempt to learn to sign, the existence of Deaf adults as fluent models of language for their children highlights a distinction that has been starkly referred to as a distinction between the 'biological parent' and the 'linguistic parent':

> *"Can hearing parents acquire sign with their children? Will they choose to? These are empirical questions, but there is a prior ethical question for researchers and child care workers in this area. How is one to define a constituency? Can one work for parents and child when their interests may not coincide? Who speaks for the deaf child: the biological or linguistic parent?"*
> (Harris, 1978, p.223)

Others have taken a more balanced view, pointing out that parents will always be the primary communicators in their children's lives and the primary sources of 'world knowledge' as deaf children develop within their hearing families:

> *"For language acquisition to fully take place with deaf children, it must be within a natural language. Because hearing parents of deaf children are not native users of ASL and since ASL is not the only way for parent-child communication to take place, it is not expected that they be models for language acquisition, rather to be an active part of the child's communication environment. What is most important is for parent and child to be interacting freely using whatever method is most comfortable. However, if parents choose to learn ASL, this can only enhance already existing communication."*
> (CSDF, 1991, unpaginated)

Even for parents who most positively support contact with the Deaf community and Deaf culture, difficult emotions arise. For a deaf child, a Deaf adult will always be in a relationship of like with like. A Deaf adult will always understand and empathise with a deaf child from within an experience of the world that hearing parents cannot share in the same way. Indeed, one of the new challenges of adjustment to a deaf child for parents exposed to a bilingual/bicultural model has been identified as these difficult emotional contradictions (Young, 1999). As has been remarked:

"Undoubtedly, many deaf children will, as adults, be active members of the Deaf community. Yet the notion of a strong Deaf community rather than offering a positive solution to hearing mothers, presents a further dilemma. In acknowledging their child is Deaf, they are in a sense losing their child to a different language and cultural group, for part of childrearing is the sharing and developing of a common culture." (Gregory, 1991, p.140)

Clearly, the way forward is a partnership between the Deaf community, Deaf professionals working with families and hearing parents. To these ends, a growing number of family support projects, led by, and employing Deaf adults to work with families, are springing up throughout the UK (Young, Griggs and Sutherland, 2000). The parenting role(s) of Deaf adults in the lives of deaf children of hearing families will always remain significant for those children growing up bilingually and biculturally (Knight and Swanwick, 1999), but it is one that requires careful negotiation and strong support of families who may find themselves confronted with difficult and potentially undermining experiences.

Conclusion

This literature review began by asking what exactly we know about *parenting* and deaf children. This is a different question from asking what do we know about parents and deaf children. It was an attempt to place the emphasis on the 'how' of bringing up a deaf child whilst giving recognition to the complex context of family and social relationships. The key dimensions of skills, identity, roles and services have provided a useful psycho-social framework for exploring the major influences on parenting a deaf child.

However, it has also become clear that there are many gaps in our understanding of parenting and deaf children and far greater investigation is needed from the perspective of parents themselves and within positive frameworks that attend to parents' own pragmatic and successful strategies.

In thinking about parenting and deaf children, it is too easy to focus on what goes wrong and what is different or problematic at the expense of a greater awareness of parents' expertise. There is much still to be learned about the process of *becoming* a parent of a deaf child over time, and how each new phase of child development brings new opportunities and challenges for parents and service providers alike.

As two parents summarise:

> "Rearing a deaf child can, in some ways, be very different from rearing a hearing child. Even though some of these experiences seem very unusual to us, <u>we know that what we have experienced, is, for our family, quite normal</u>. We intend to continue learning and to proceed with, what we feel are the key ingredients to success and happiness: communication, love and support."
> (Burgess and Burgess, 1995, p.173, report author's emphasis)

> "Raising a deaf child, especially if you are hearing, is a completely different experience from what you expected or from what your hearing friends are having. Very little in your past can help you. Inevitably what will see you through is a lot of love and truckload of energy." (Gansberg, 1995. p.323)

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Appendix – details of needs assessment strategy and methodology of the literature review

In order to address the difficult conditions surrounding the nature of the literature review previously described, a two stage search strategy with clearly defined inclusion and exclusion criteria was adopted to establish the literature set on which the written review on parenting and deaf children would be based. Whilst this review has no pretensions to being a systematic review within the formal definition of the term, it has borrowed from the principles of systematic reviewing in its construction (Lloyd, 1999 p. 72-74).

Stage one search strategy

Following the principle of going from the known to the unknown, stage one consisted of seeking out literature that directly addressed the concept and practice of parenting deaf children, where "*parenting*" *is taken to encompass the role(s), tasks, activities, resources, skills and experiences of being a parent of a deaf child.*

It is acknowledged that this definition is somewhat pragmatic and open to considerable interpretation. However, it was the best fit that could be found for defining the literature to be considered without being so rigid as to exclude potentially relevant material from tangential sources, eg the literature on parenting disabled children.

To these ends, a variety of stage one search strategies were employed:

Electronic databases (and search terms)

Three electronic databases were consulted: PsychInfo; BIDS (Bath Information Data Services), and ERIC (Educational Resource and Information Center). The search terms used were 'parenting + deaf' in order to identify literature of highly specific relevance and 'parenting' in order to identify literature of more tangential relevance, eg literature linked to parenting and disability, or parenting and culture, but which may include within its sample deaf children.

Literature available from and known to the commissioning organisation

This work was commissioned by NDCS, an organisation specifically aimed at supporting parents of deaf children. It was able to supply a range of its own literature and also through contacts with its sister organisations.

Pre-existing knowledge of the field/resources

The principal author has a PhD in aspects of early intervention with parents of deaf children and has published in this field before. She therefore already has a body of knowledge of relevant literature on which to draw.

To all of these search strategies, the following inclusion and exclusion criteria were also applied.

Inclusion criteria

- Literature written by professionals/academics for parents of deaf children, and that is aimed at supporting/explaining the experience and challenges associated with bringing up a deaf child and promoting the skills required.

- Literature written by professionals/academics that examines aspects of the needs, tasks, roles, skills and experiences of parenting a deaf child but is not necessarily written for parents themselves.

- Literature by parents of deaf children themselves, that seeks to explore the experience of being a parent of a deaf child and which discuses aspects of parenting from an 'insider' perspective.

- Literature by D/deaf people that reflects on the experience of having been parented.

- Literature developed by deaf organisations, and statutory and voluntary services aimed at supporting parents in bring up a deaf child.

- Electronic resources, largely web-based, run by and for parents of deaf children.

Exclusion criteria

- The scope of the study and the literature review does not encompass D/deaf parents of deaf children.

- The majority of literature prior to 1980 is excluded. [This decision was taken in order to focus on that literature which is still likely to be in current use by parents and professionals, rather than that which historically may have been of interest. Where a pre-1980 key text was known still to be of significance in the field, it was included, eg Gregory, 1976.]

- The literature search/review took place April-July 2001 and, therefore, any literature published after that time period is likely to be excluded.

- Whilst world literature is not specifically excluded, there is a bias towards literature from the UK, the USA and that which is written in English.

- Whilst there is not a specific exclusion criterion relating to age of child, there is an inevitable bias towards literature relating to the early years of child development and the period post identification of hearing impairment/deafness as this tends to generate most published material.

Stage two search strategy

The stage one search strategy did not necessarily identify material relevant to parenting and deaf children that might be *embedded* in a variety of deaf - related literature that would not be 'hit' by an electronic search according to 'parenting + deaf' or 'parenting'. However, some of the other search strategies employed in stage one did do so – ie professionals, academics and organisations inevitably have knowledge of (or generate themselves) literature that they know and use as relevant to parenting and deaf children, but which may not be labelled as such.

Therefore, the stage two search strategy consisted of a 'snowball' procedure of following up the references and bibliographies of stage one identified literature to expand further the body of literature identified as relevant to parenting and deaf children. Inevitably, this snowball process itself could have many stages, as one reference leads to another and so forth.

The inclusion/exclusion criteria for the literature yielded by the stage two search strategy were much harder to define. Whilst all of the exclusion criteria for the stage one search strategy clearly applied, the specific inclusion criteria were less applicable, given that we were dealing principally with embedded information (eg conclusions from a study on social support that have implications for parenting practice, but where the study itself makes no claims to be about

parenting). In the end, decisions about which material to include from that identified through the stage two search strategy was based on three criteria – two of which were essentially judgements made by the author:

Inclusion criteria for stage two search strategy items

- That the items are not automatically excluded according to the criteria set for the stage one search strategy.

- That they contain material relevant to the notion of parenting that underpinned the stage one search strategy, where "*parenting" is taken to encompass the role(s), tasks, activities, resources, skills and experiences of being a parent of a deaf child.*

- That, from a pragmatic perspective, the material is relevant to the task underpinning the literature review – namely, that it will inform the development of the "parents' toolkit".

Whilst this third criteria may seem somewhat arbitrary, it was designed to force some specific judgements about what this working notion of 'relevance to parenting' might mean. For example, much of the new work on theory of mind and deaf children will ultimately have important implications for our approaches to deaf children's linguistic and social development (Lundy, 2002). However, in terms of developing a resource for parents' use, many of its cognitive psychological insights are, as they are currently applied, of only a distant relevance.

Building a framework

Having established the core literature set, the works were read, and detailed notes were taken of relevant material. A content analysis was then carried out on the notes pertaining to each literature item, in order to define a series of thematic categories under which the relevant material could be re-classified. This process initially yielded 21 theme areas.

Having gone through this process, it became clear that these categories could be refined further into four essential theme areas that could then be used as a framework for focussing and presenting the available literature on parenting and deaf children. These thematic headings in turn encompassed a range of often diverse work on the four key themes of this review: skills, identity, roles, and services.

The National Deaf Children's Society is an organisation of parents, families and carers which exists to support parents in enabling their child to maximise their skills and abilities; and works to facilitate this process by every means possible.

Its fundamental role is to advocate for parents and carers as and when appropriate, whilst at all times ensuring the child's welfare is paramount.

NDCS services include:

- Providing clear, balanced information and advice on many issues relating to childhood deafness

- Advice on audiology, including information on glue ear

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- A children's equipment fund (subject to availability) and an opportunity to try equipment in the home and at school

- Support with benefits claims and Disability Appeals Tribunals

- Education advice and support at Special Educational Needs Tribunals/Appeals

- The Listening Bus™ which travels around the country with the latest technology

- Annual technology exhibition and conference

- Family weekends, special events and training for families of deaf children

- *TALK* magazine and a range of publications for both families and professionals, some leaflets in community languages

- A network of regional staff and local contacts

- Training and consultancy for professionals

- Personal development training for young deaf and hearing people

- Sports, arts and outdoor activities for young deaf and hearing people

*If you prefer to use a spoken language other than English, tell us the language of your choice and your telephone number (in English). Within a few minutes, we will ring you back via an interpreter.

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