

Universal Newborn Hearing Screening and Early Identification of Deafness: Parents' Responses to Knowing Early and Their Expectations of Child Communication Development

Alys Young

Helen Tattersall

University of Manchester

This article presents results from an interview study of 45 parents/caregivers (representing 27 families) whose infants were correctly identified as deaf during the first phase of the implementation of the national universal Newborn Hearing Screening Programme in England. Average age of children when parents were interviewed was 25 weeks. Two issues are explored: (a) how parents talk about significance of knowing early that their child is deaf and (b) parents' expectations of their child's development in light of early identification. Although results demonstrate clear support from parents' perspective of knowing early, they also identify the psychological complexities of recognizing both the grief and reassurance that early knowledge brings; the risks of early knowledge-inducing timetables of expectations that create distress when not met speedily; the extent to which parental models of the developmental advantages of early identification are underpinned by notions of normal speech and the possibility of being like hearing children; and the pervasiveness of deficit and illness models associated with having identified deafness early. Implications for parental support and professional responses are also discussed.

With the rapid expansion of Universal Newborn Hearing Screening (UNHS) programs across both the developed and the developing world (Newborn Hearing Screening Conference, 2006; <http://nhs2006.isib.cnr>).

We are grateful to all families who participated in this study and who have given us the opportunity to learn from them. This work was undertaken by the evaluation team of the first phase implementation of the NHSP in England, which received funding from the Department of Health. The views expressed in the publication are those of the authors and not necessarily those of the Department of Health. No conflicts of interest were reported. Correspondence should be sent to Alys Young, School of Nursing, Midwifery and Social Work, University of Manchester, Coupland III, Oxford Road, Manchester M13 9PL, United Kingdom (e-mail: alys.young@manchester.ac.uk).

it/) has come a host of new questions for both research and practice. Interest has largely focused on the separate but linked concerns of demonstrating developmental gain (Kennedy et al., 2006; Moeller, 2000; Wake, Poulakis, Hughes, Carey-Sargeant, & Rickards, 2005; Yoshinaga-Itano, 2003; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998) and understanding what makes for effective early intervention (Calderon, 2000; Moeller, 2001; Stredler Brown, 2005; Stredler Brown & Arehart, 1998). After all, early identification is of little importance if it is not combined with quality services that can realize for children and families the potential advantage of significantly earlier diagnosis than had previously been the case. Questions have begun to be raised about potential bias in the design of some earlier studies (Kennedy et al., 2006; Wake et al., 2005), the strength of the evidence base overall (Thompson et al., 2001), and the failure to account fully for the diverse nature of family and linguistic interventions associated with the UNHS programs studied (Janjua, 2005). However, despite these questions, the evidence remains compelling of substantial linguistic and socioemotional developmental advantages associated with early identification (Yoshinaga-Itano, 2003).

Within this rash of activity, far less attention has been paid to the impact of the deaf child on the family and processes and patterns of family adjustment. In many respects these are old concerns (Gregory, 1976; Young, 1999), and one may well ask why they might deserve any special attention in light of UNHS. After all, issues we have always known to be important in

understanding differential outcomes for children and families are not going to change, for example, stress and social support (Calderon & Greenberg, 1999), quantity and quality of linguistic environment (Marschark, 1997, 2000), adaptability and cohesion (Calderon & Greenberg, 2000), and quality and nature of family relationships (Bodner-Johnson, 1985). All focus our attention on the reciprocal impacts of deafness, child, and family. However, newborn hearing screening and early identification provokes a changed set of circumstances in which we are invited to understand early family experiences of deafness (DesGeorges, 2003) and inevitably to question their impact on our knowledge of parental reactions and adjustment to childhood deafness. In this respect, and in the following, the focus of this article is only on hearing families with deaf children.

What is meant by changed circumstances associated with early family experiences of deafness? Firstly, there is a changed discovery mechanism. It is now a routine and medically driven, “institution-initiated” (Luterman, 2001) process, rather than one that, in the vast majority of cases previously, had been significantly informed by parental observation and discovery. Secondly, there is a highly compressed timescale between birth and identification of deafness. In England, for example, the average age of identification is now 2 months old in comparison with 26 months previously (Davis et al., 1997). Thirdly, the identification of deafness occurs at a much earlier stage of relationship formation between parent and child. It is integral to the earliest experiences of getting to know the new family member. Fourthly, early intervention occurs very quickly in the child’s life, intensively and essentially as part of the same process of birth–screening–identification–diagnosis–intervention. In the United Kingdom at least, pauses or deferments in such a sequence are unusual.

A limited number of studies are beginning to investigate the effects of such changed circumstances on aspects of parental and family adjustment to childhood deafness; however, the evidence in most cases is still rather weak. Siegel (2000, as cited in Yoshinaga-Itano & de Uzcatogui, 2001) suggests that earlier identification can lead to a quicker resolution of parental grief processes among hearing parents. However, this conclusion derives from a small pilot study comparing parents of earlier and later identified deaf children

and does not differentiate between the early identification and/or improved language development as the mediating variable. Lederberg and Golbach (2002) suggest that the lack of high levels of parenting stress they found during preschool is a measure of the success of intensive early intervention. They further remark that these findings reinforce the importance of early identification and consequent enrollment in early intervention programs. Nonetheless, concerns have been raised also that knowing early may be too early for some families (Gregory, 1999, 2001) and may actually interfere with the normal processes of early bonding (Yoshinaga-Itano & de Uzcatogui, 2001). In effect, parents are unable to enjoy their newborn as their baby before they have to engage with both the knowledge of deafness and the services and professionals that come with that knowledge (Luterman, in press). Equally, one could argue that there might be better bonding because parents know very early on that they are forming a relationship with a deaf baby, rather than experiencing later on a break in their relationship as they discover their child is different from how they had previously thought. There is no strong evidence either way.

Given this context, the research evaluation of the first phase of the implementation of the national universal Newborn Hearing Screening Programme (NHSP) in England (Bamford et al., 2005) afforded the opportunity to contribute to the limited evidence base on the impact of early identification of deafness on hearing families. Taken from a qualitative interview study of 45 hearing parents of newly identified deaf children (the true case study), the following analyzes two aspects of parental experience: (a) how parents describe the significance and impact of knowing early that their child is deaf and (b) parents’ very earliest assumptions about the impact of early identification on their deaf children’s development and in particular their communication.

Method

Introduction

The overall evaluation of phase one of the introduction of NHSP in England contained a number of discrete but linked research studies (see Bamford et al., 2005).

One of these was the “true case study.” This was the study of families whose children had correctly been identified as deaf following screening. It is from this study that the following data are drawn.

Aims

Overall, the true case study had three aims:

- to evaluate the impact of the screening process and its consequences for intervention from the perspective of parents;
- to explore key personal, family, and sociodemographic influences on that experience; and
- to enable parents to contribute to the identification and definition of what is good practice in newborn hearing screening.

Results reported in this paper refer to the analysis of only two data segments; those associated with parents' descriptions of knowing early and of their expectations of language development. Other data segments pertaining to different subjects within the study have been reported elsewhere (McCracken, Young, & Tattersall, in press; Tattersall & Young, 2006; Young & Tattersall, 2005a, 2005b). In a rich qualitative data set that is analyzed thematically (see below), it is not unusual to isolate differing strands and to analyze and report these in depth.

Methodological Approach

The methodological approach is a qualitative one. Parents are invited to tell their own stories, in their own words within the broad framework of covering the following: the experience of the screening from first screening test, through referral and diagnostic assessment to confirmation; the experience of early intervention and professional support; and their advice to other parents and professionals engaged in the same process. The interviewer's job is to clarify points in the narrative as it progresses to ensure information is collected about comparable events across all interviews undertaken; to support the narrative telling through empathic engagement with the teller; and to record the interview for later analysis. In this way, parents do not respond to a set of rigidly predefined questions in which to fit their

experience, but rather are given the scope to make decisions themselves about what is meaningful and important in their experiences within some consistent parameters applied to all interviews. (Further details of methodological approach can be found in Young, Tattersall, Uus, Bamford, & McCracken, 2004.)

The sample was a purposive one because only those parents whose children fulfilled the definition of a true case identified by NHSP could be invited to participate. To be classed as a true case, the child had to meet the criteria of having “a permanent bilateral hearing loss with hearing threshold \geq 40 dB HL based on the average in the better hearing ear at 0.5, 1, 2 and 4 kHz” (www.nhsp.info).

Between the period December 1, 2002, and December 31, 2003, the evaluation team was notified of a total of 108 true cases by the appropriate audiology personnel located in each NHSP phase one site. Once notified of a true case, the researcher requested that the parent letter and information sheet detailing the study be sent to the parents/family by the audiology personnel in each location. (At this point, the name and address of the family was unknown to the researcher.) Families who wished to be involved in the study were asked to complete a response sheet with their name and address and send it directly to the researcher; an interview would then be arranged. If no response was received from the family after 3 months, a reminder letter was sent out. There were no further reminders. The study was approved by Medial Research Ethics Committee www.corec.org.uk). For full details of the recruitment methods used, the creation of parent information materials in diverse languages, and a discussion of the ethical issues involved and the challenges of sampling, see Young, Tattersall, Uus, Bamford, and McCracken (2003).

Of the 108 notified true cases, 91 families were invited to participate in the study. (Ten families were excluded from the true case definition because their child had an auditory neuropathy¹; in 5 cases, the child died and so the families were not contacted; and in 2 cases, it proved unclear whether the child would fulfill the true case criteria or in reality be found to have a temporary conductive loss.) Of these 91 families, 28 responded positively and 27 were interviewed. (In one case, the response was too late to enable data collection.)

Characteristics of the Sample

Respondents were encouraged to choose who should be present at the interviews depending on who had most involvement with baby and had experienced the screening process. Consequently, 27 interviews equated to participation from 45 parents/caregivers/extended family. In 12 interviews, only the mother was present. In 11 interviews, both mother and father were present. In two interviews, mother and grandmother were present. In addition, one interview consisted of mother, father, and grandmother and another of both parents and two grandparents.

In 25 of the 27 cases screening took place within hospital, with only 2 having experienced community-based screening. Six babies in the sample were drawn from Neonatal Intensive Care Unit population. Two of the participating families had other deaf children. Of the 27 infants, 22% had disabilities/illnesses (e.g., epilepsy, heart defects, visual impairment, and developmental delays) that had been identified by the time of the interview. In 11 of the 27 families, the deaf child was their first child. Four families were drawn from black/minority ethnic backgrounds, and two others were cross-cultural families. All parents/caregivers were “hearing” (but two had unilateral losses). There was a bias in the sample toward high-income families (12 of 27 had family incomes of £35,000 or over, equivalent at the time to approximately \$56,000). In three cases, languages other than English were used in the interviews and interpreters were used. The distribution of degree of deafness in the babies in the sample is roughly equivalent to that one would expect in the general population of deaf children: 44% moderately deaf, 19% severely deaf, and 37% profoundly deaf. How long after a confirmation of their child’s deafness parents were interviewed depended on them, in that they triggered the wish to be involved in the research. The average time that interviews took place following confirmation was 25 weeks (range 8–51 weeks).

Data Collection

All parents chose to be interviewed at home, with length of interview averaging 1.5 hr. Where parents’

preferred language was other than spoken English, they were offered an interview by the regular researcher using an interpreter or an interview by a specially recruited additional researcher who could use directly their own language. All chose the regular researcher plus interpreter. (For a full discussion of methodological considerations in qualitative research involving interpreters and data translation, see Temple and Young, 2004). In addition, parents completed a simple questionnaire to collect sociodemographic information. The evaluation team working on this part of the study was experienced in the use of qualitative data collection methods and particularly with parents of deaf children.

Analysis

Data were audio recorded and transcribed in full. A thematic content analysis was carried out with the assistance of the sort and retrieve program QSR NUD*IST 4. Codes were generated independently by members of the research team and then compared for consistency or deviance. Where there were disagreements, further discussion with reference to the transcripts lead to the final coding framework. As the analysis progressed, some codes were collapsed into others as it became apparent they were capturing the same/overlapping experiences. The analysis used cross-sectional techniques from both “within-case” and “cross-case” perspectives (Silverman, 2000). A “case” is regarded as an interview (i.e., there were 27) rather than an individual (there were 45 participants). Within-case perspectives pay attention to similarity/difference of response between participants within the same interview. Cross-case analysis considers shared and disputed perspectives between the experiences contained within the 27 interviews.

The following treats each of the 27 interviews as its own case. Numbers in brackets after quotations are identifiers for which interview the extract is taken from—thus allowing the reader to track the diversity of cases used. The first number refers to the case; the second number to the age of the deaf child in months at the time of the interview; and the final letter to the degree of deafness in audiological terms, that is, P = profound, S = severe, and M = moderate. We chose

to code data extracts in this way to be transparent about the extent to which particular attitudes may be associated or not with variations in the children's ages at the time of interview or degree of deafness. Additionally, if couples were interviewed together, then attribution is given to whether it was the mother's or father's comments that are being represented.

Results

How Did Parents² Talk About Knowing Early?

The overwhelming majority of parents, in 21 of 27 interviews, were unequivocally positive about the fact that their child's deafness had been identified early, regardless of how young/old the infant was at time of interview and regardless of degree of deafness.

It can only be a good thing to find this out. [6,7,M]

None of these thought, however, that knowing early took away the shock, grief, or loss they associated with having a deaf child.³ Parents described the impact more in terms of a trade-off. Namely, these feelings were bound to have happened at some point, it was just that they were happening earlier.

[24,4,P mother]: Breaking the news is going to be shitty at any stage isn't it really? It is a particularly vulnerable time for parents 'cos of the tiredness and things like that, but that's just one of those things . . .

[24,4,P father]: . . . If you're diagnosed with cancer, you don't go 'oh it's a shame it happened this week "cos it's ruined this week," you go "you need to know at some point, the sooner the better."

Clearly you go through the process of we well, almost grieving which is a gradual process, but that would happen at one point any way, when the child is two or three so there's no way you could avoid it . . . things would be vastly different if he was three and it was happening now, but if it's happening at such an early age, you're not worrying too much about it. I'm sure things will turn out ok. [11,10,P]

Also, although such feelings might be difficult, the positive group of parents did not suggest they wanted

to avoid them because to do so would be to want to avoid also the advantages for their children that came with knowing early.

. . . sometimes you think oh maybe, maybe it would have been nicer to have found out later on but I think oh no, that's selfish because . . . she would be missing out . . . it was obviously good you know, to have found out from the point of view you can get the hearing aids in and start helping her . . . [2,5,P]

Early identification was also positively associated with having more time to come to terms with grief. Whereas for some parents this was expressed as having more time to "deal with things" earlier, for others it meant having more time not to deal with things. Both responses were in effect possible routes through their grieving process.

The distress of learning that their child was deaf was also significantly moderated by a sense of reassurance that grew directly out of knowing early.

We just feel so lucky that she has been picked up and we know that she's going to have as much help as she needs and she's going to be able to do as much as she can with it being part of her life. [1,6,M]

This reassurance was expressed in a variety of ways. For some, the reassurance stemmed directly from being clear from the beginning that their baby was a deaf baby. For example, six parents talked about being able to avoid the guilt they would have felt in the future about their parenting if they had acted as if the baby were hearing only to discover later she/he was deaf. One mother told us how she could imagine she would have thought her child was just being "naughty"; another that she might have thought her child "stupid"; another spoke of the sense of responsibility she would have felt for the child's missed opportunities if she had just carried on as if he were hearing. The reassurance of early knowledge of the child as a deaf child was also, for three parents, expressed in terms of being able to tune in appropriately to their deaf child's needs and responses from the earliest time. One mother spoke movingly of how "frightening" it must be for her baby and, therefore, how glad she is she knows and so can

adapt. For another father, it was the advantage of being able to get expectations right:

the finding out early is essentially a good thing both medically and in terms of communication skills, but also emotionally . . . right from the word go, you'll know your child has a disability and you learn to cope with it and your vision and your hopes and your dreams for your child are tailored and focus given to that disability. [but] if at 2 years your child is diagnosed deaf, you've had two years of dreaming that your daughter is going to be the next pop star or primeminister or whatever your dream is and that's shattered . . . [24,4,P, father]

Overwhelmingly, however, the reassurance stemmed from the sense of being able to take action and being able to do that quickly.

Detect it then like getting in front wi'tit. [26,11,P]

Parents talked in terms of how, without early identification, the child would have missed out on support that could have helped. Avoiding the possibility of such regrets was important. They also valued the fact that there would be no unnecessary delay in doing something that might help their baby (such as fitting hearing aids or a referral for a cochlear implant). The possibility of having time to learn and develop skills now that would be helpful in the future as their child developed (e.g., sign language) was also important. For others, the essence of the reassurance of knowing early lay in not feeling helpless. They as parents could do something about it. Many talked in terms of preparation for the job ahead. For others, the value lay in the potential, right from the start, for the child to get used to what parents saw as characteristic consequences of being deaf, such as wearing hearing aids.

In short, the vast majority of parents were clear that knowing early was positive. It was not easy, it did not necessarily lessen their distress nor take away their sense of grief, but these feelings were weighed against recognized advantages of early identification that in different ways were comforting.

In the case of five of the 27 interviews, the picture was different. These parents had initially shared positive attitudes as expressed by others, but these first responses had been eclipsed by a perceived lack of

action from professional services. Examples given included earmolds still not fitting adequately, digital hearing aids not working properly, delays in acquiring new hearing aids, and being unable to secure a referral for a cochlear implant. At the heart of these concerns was as an unfulfilled expectation, not just that early identification would lead to effective action but that this would happen quickly. Furthermore, if it did not then there was a perceived sense of the child "losing ground" and that the advantages of knowing early were being lost through ineffective support. These parents talked as if they were on a timetable, and when, for whatever reason, this was disrupted, then the effects were perceived as serious because they were hampering the developmental advantage that was coming from early identification. Note the frustration and distress expressed by these two parents, both of 4-month olds:

the whole thing about this newborn hearing is that you tackle it at an early stage and basically get the nerve ending, the auditory nerve to sort of work at an early stage and we haven't achieved that yet because we've not obtained . . . that level in the digital ear we should have . . . at the moment he is not benefiting at all, so we're still four months behind, we're still four months behind, we haven't benefited from this newborn hearing. [27,4,P, father]

And in response to a 3-week delay in acquiring new hearing aids:

. . . every week and every month that goes by and his hearing isn't enhanced he is going to delay his learning experience and that's your priority now you know as a parent, now our priority is to ensure that he stands every chance of integrating into mainstream school and acquiring language to the best of his ability and having the best chance in life. [5,4,M]

A further two mothers were quite clear that they wished that they had not known early that their child was deaf. Both talked in terms of not being able to enjoy their babies. One described living with the aftermath of what had been a worrying screening and identification process for her. Even though that had

resulted in a definitive diagnosis, the emotional effects of that very early anxiety were ones that she felt were still having an influence:

You're basically left with the worry then we came home and rather than having the joy of bringing a new baby home all we had in our head was worry . . . if we could go back and have it just at 6 weeks or even a month. [13,12,P]

The other compared her experiences with her deaf child with those with her hearing child.

I suppose if the child has got a hearing loss then the sooner you know about it and the sooner you can do something to help the better. But from our point of view it has been a nightmare really. I wish I hadn't been told I wish I was just finding out now because I would have had nearly 8 months to just enjoy him. It has actually been 8 horrible months on and off. It hasn't affected me bonding with him or anything but I have not enjoyed him, like I did [my other child]. I wish I had never been told. I wish I was just finding out now . . . [19,8,M]

The background issues for this mother were numerous hospital visits and ongoing uncertainty about how, audiologically, to manage her son's hearing loss. In other words, in both cases the dissatisfaction associated with knowing early arose in part from the intervention consequences of that knowledge and not from the knowledge per se.

How Did Parents Talk About Expectations of Language Development?

In 10 interviews, parents expressed expectations that their child would reach what they regarded as normal developmental milestones; would be very close to them; and would be able to manage successfully in mainstream education on a par with their hearing peers.

It won't hamper their development or their progress in any way. [19,8,M]

Of these 10, five children were moderately, two severely, and three profoundly deaf. Parents linked these expectations firmly to the connection between early

identification and consequent early hearing aid fitting, leading to normal speech development. These were connections that had been reinforced by the professionals they had encountered and which were highly reassuring to them:

It was a kind of reassuring thing . . . they are the ones that told us because we have caught, you know caught it early . . . then you know the chances of her going to a mainstream school and speaking normally are so much better. So they put that positive thought in your head kind of things, which is obviously what you want to hear, but it's not that you just need to hear it, you know it's the truth. [20,5,P]

As [Teacher of the Deaf] says, the children who are picked up when they are 6 or 7 months old, you have to teach them to listen, whereas he's actually just come along with it, he knows how to listen . . . so it's just like all positive, and she said like because Michael is so young being picked up we expect him to be even more sort of normal . . . he's not missed out on 10 months of noise, we haven't got to make up for that. [9,5,S]

In eight other interviews, the point made by parents was not an expectation of normal development, but rather the avoidance of abnormal development. This notion of abnormality was defined by what was perceived to have been previously common problems in deaf children's development. Problems that now could be avoided because of early identification and early intervention. Again, most parents' comments were predicated on the significance of early sound and early hearing aid fitting.

Had we not found out we would have lost so many months and he'd have developed in a different way . . . when you just observe him you know he does so much more than he probably would have done had we not put the hearing aids on . . . [7,15,P]

Obviously they reassure you and sort of help with all of that and say "you know . . . especially as we've [caught] it so early, there's every you know . . . encourage her to speak as well as possible." [2,5,P]

Noticeably, parents retold to us stories gleaned from professionals of what had been presented as the dire

consequences in the past of not having had hearing aids fitted early.

The Teacher of the Deaf told us that after 6 months if they can't hear nought back when they're babbling, then they just completely stop talking ... Between the 6 months and the 18 months that is a big communication gap in a child's life. That is an awful lot to miss out on. If you catch them before that you like get the hearing aids in like when they are 3 months old or something to keep them babbling so they are hearing so they will keep on. [15,10,M]

We were told if it wasn't diagnosed then perhaps she could go off in her own little world and maybe like baby babble or talk whatever you want to call it, would eventually fade away. So by Sally having her hearing aids so early it has given her like that step up if you like so she has had that advantage of having them earlier so if Sally was normal she would be able to achieve and go in the right path roughly about the same age of a normal child anyway. [22,14,S]

In two interviews parents talked very differently. They were less concerned about thinking about ensuring trajectories of normal development and more concerned about ensuring enhanced developmental environments for their children in a broader sense. These were parents who made a strong link between knowing early and being able to tailor their interactions to take advantage of that knowledge for their child's benefit. Examples given included discussion about developing mutually rich ways to communicate (regardless of language or modality); learning how to moderate speech to tune in to the child; and learning how to be sensitized to play in ways that would be appropriate for their child's developmental needs.

I think her advantages are gonna be that we're aware that she is not hearing low level voice or sound or whispers or fine music from some of the toys or whatever, especially when she's chucked those out of her ear, so we can relate to her and play games with her and talk to her in a way that she is going to pick it up. [4,5,M]

Interestingly, both families concerned had children with moderate hearing losses. In one case, the parents already had a deaf child. In another, the parents had

a deaf role model who visited the home as well as a teacher of the deaf. The mother herself made a link between her own attitude to her child's development and learning things from the deaf home visitor like how to enjoy playing with language (both visual and auditory) while changing the baby's nappy.

In the other eight interviews, in one case the parent offered no comments on their child's development; three, in broad terms, had positive expectations of their children's development but offered no details; one child had complex developmental disabilities and deafness was not the priority issue in parents' view; two interviews were predominantly concerned about issues of screening process and diagnosis and almost nothing was discussed about child development; and in the final one, the parent was of the view that deafness was just such a big developmental disadvantage there was not much that could be said about the child's future development beyond that.

Discussion

These data have afforded us a rare snapshot of parents' earliest responses to the changed condition of knowing very early that they have a deaf child, how they envisage the future development of that child, and the links they make between the two. In discussing the significance of their views, it is important to remember that in all but two cases, this was parents' first experience of deafness and in 11 cases this was their first experience of parenthood. We know from many previous parent accounts that their journeys are long ones during which understanding grows, knowledge is slowly or quickly acquired, decisions are made and remade, different directions taken from those originally envisaged, and differing and conflicting professional views regularly encountered (DesGeorges, 2003). Therefore, in discussing what we can learn from these very early thoughts, it is important to see them in the context of an evolving landscape for parents (they may have very different views in 3 years time) whilst at the same time treating their narratives as of-the-moment-evidence to help us understand the new questions of the impact on parents of very early identification.

Our first response, therefore, should perhaps be to ask whether in these accounts we are seeing anything

different from what we might have expected to see when diagnosis more normally occurred later on in childhood? It is hard to generalize, but some trends can be picked out. We have always known that grief associated, for hearing parents, with the confirmation of their child's deafness is a complex response (Luterman, 1999). While perhaps following identifiable stages to some kind of initial resolution, it has the power to reoccur at different points as the child grows up (Wikler, Wasow, & Hatfield, 1981). Although it has often been erroneously assumed to the dominant explanatory variable for how parents might respond to their children (Kampfe, 1989), it nonetheless remains a powerful, psychological, and emotional response that influences parental behavior and decision making. Our data have added further to the complexity of this picture. It has challenged any simple propositions that might be made about how early identification in some way lessens grief or enables its quicker resolution. In many ways, it sets it in a more precarious context.

Firstly, the majority of parents in our interviews were left with the difficult psychological state of the synchronous emotions of grief and being positive about the knowledge that has led to the grief. Secondly, the reassurance that the vast majority acknowledge derives from the possibility of taking action and/or avoiding the retrospective guilt of inaction is overwhelmingly dominant. Although not wishing to deny that the feelings of being able to do something and to some extent take control are helpful in resolving distressing psychological reactions (such as grief), it is perhaps worth pausing to ask whether there are not risks also in this. A focus on activity can equally serve to avoid or deny feelings that are important in the process of coming to terms with an event that has disrupted an expected life pattern (in this case, the birth of a deaf child to a hearing family). There was also evidence from some parents of perceiving themselves to be on a timetable and under pressure to perform within that, otherwise somehow their child would lose ground and the early advantages would be lost. For a few, this sense was clearly a source of pressure and further distress, an outcome perhaps all the more disturbing if we remember just how young these infants are and how early on in the parent-child relationship these concerns were being raised.

These findings, perhaps serve to indicate that in supporting parents, one of the new challenges of early identification is to be mindful of the need to create the space for parents to feel their responses to their child's deafness (and how those change) and not for that psychological process to be disallowed (by self or others). Also, the parameters of what we have regarded as the grief response are now changed in emphasis, as parents balance the difficult emotions of knowledge bringing grief and knowledge bringing advantage at one and the same time. Furthermore, for some parents knowing early does seem to create time—a sense of having time to get used to things, make plans, prepare for work ahead, and know their child as a deaf child right from the start. For others, it creates a sense of losing time—that the best possible outcome will only be realized if action occurs quickly and on time, an expectation that may fail them with consequent frustration, anger, and distress.

There is also at work here a potent promise of normalization (or at least parents' interpretation of such a promise). The normal or near-normal possibilities held out for deaf children are almost exclusively defined in terms speech and hearing and according to the standard of what is a normally developing hearing child. Parents are encouraged into a worldview in which their children will be different from deaf children in the past. The NHSP in England has never been founded on an assumption of an automatic connection between early identification, maximal spoken language development, and the normalization of deaf children into hearing children. The approach is much broader in seeking optimal development with recognition also given to sign language as a potential first language of deaf children, the importance of Deaf culture, and implicitly, therefore, the recognition of Deaf identity. Yet for these parents, in the overwhelming majority of cases, the notion of what might be normal for a deaf child was totally missing. By normal for a deaf child, we mean two things. Firstly, a recognition of deaf children being normal in their own terms (not by comparison with hearing children) as exemplified by the developmental trajectories of signing deaf children, whether from deaf or hearing families. Secondly, a linked and more broad understanding that deaf children will develop characteristically as deaf children

(whether we are talking about spoken or signed language), may have different learning patterns and cognitive strengths, as well as vulnerabilities in comparison with their hearing peers (Marschark, Convertino, & LaRock, 2006). However, for the vast majority of these parents, normal meant, “as if hearing,” and that is the great promise they repeated to us in these interviews.

It is important at this point to emphasize that in analyzing parents’ responses in this way, we are not seeking to be judgmental and in fact it is vital not to be. These parents were in the very early stages of their lifetime of experience. However, what they are teaching us is to be mindful, as professionals, of the constructs of deaf children that may be transmitted to parents in the earliest stages, constructs arising out of how the consequences of early identification are being interpreted and communicated. What parents may want to hear (that everything can be normal, where normal is the familiar and expected) may not ultimately serve them well. We know from work prior to the age of UNHS that parents often feel betrayed later on in their children’s lives, where the possibilities they were originally offered for their child’s development fail to be realized—particularly, in cases where oral language trajectories were pursued to the exclusion of all others (Gregory, 1995). Theoretically, the developmental advantages from early identification plus early intervention should enable us to be more confident that such results will not be repeated in the future, and this, we surmise, lies behind the stories from professionals that parents repeat, of the avoidance of previous problems. However, the evidence for the long-term development of early-identified deaf children is still being formed, and there is a vast amount that is still simply not known. Not an easy, or perhaps desirable, message to convey to parents in the earliest stages of their adjustment to a deaf child in their family, but a significant challenge inherent in the future decisions parents will make on behalf of their deaf children.

The final issue to be raised concerns the discourse underlying many parents’ comments. This piece of work was not a discourse analysis; nonetheless, one cannot escape noticing the casual expressions of illness and treatment that permeate many parents’ comments cited. Deafness is “caught early” as if an illness or

disease. It is a problem that can be transformed. One father, as cited previously, made a direct comparison with cancer and the importance of early diagnosis. The expectation of normalization into hearing speaking children is underpinned by assumptions of deafness as something to be fixed and the gold standard of achievement being to match hearing peers. There is a paradox here. Behind the drive for early identification and better early intervention lies a strong and, in the opinion of these authors, a correct assumption that it is fundamentally wrong to believe that deaf children by dint of deafness are not capable of development and achievement within the normal range and diversity of those that hear. However, there is a world of difference between talking about developmental outcomes comparable with hearing children and talking about deaf children developing as hearing children, where the latter seeks to minimize or deny the ways in which to be deaf is to be different from being hearing. The distinction is perhaps not one to be expected from parents at such an early stage in their child’s life and touches on fundamental questions of identity, diversity, and acceptance. Nonetheless, perhaps we should be worried that the model of deafness that is so prevalent in these early discussions with parents is one predominated by a medical model of deafness and that that appears to be parents’, at least in this sample, most early influence.

Conclusion

Early intervention is rapidly changing in the wake of UNHS. This is not only a question of new approaches and technologies but also about how to support and counsel parents (and with parents) through those processes of what DesGeorges (2003) describes as “reaction, acceptance and advocacy.” These results help us to begin to understand the ways in which the earliest experiences for parents are both the same and different from those we have previously known and provide some direction about sensitive areas of interpretation and professional discourse to be mindful of in tailoring parent–professional encounters in the changed conditions of early identification. The long-term patterns of parental adjustment in light of UNHS remain almost totally unknown.

Notes

1. Despite fitting the true case criteria, children identified as having an auditory neuropathy were excluded from this particular study. This decision was taken because it was felt that the degree of uncertainty relating to this condition would mean that these families' experiences of screening would be significantly different from the experiences of the majority of parents of true cases.

2. For ease, we are using the term parents to indicate the individuals who participated in the interviews. Included within this set, however, are other extended family members, as noted, who were principal carers in the babies' lives.

3. Parents used a whole variety of terms themselves when talking about their children including "deaf", "hearing impaired," "child with a hearing loss," and "disabled." In the interviews themselves, we followed their practice and used their description of preference. However, in this article we have used one term "deaf" to apply to all children concerned.

References

- Bamford, J., Ankjell, H., Crockett, R., Marteau, T., McCracken, W., Parker, D., et al. (2005). *Report of the evaluation of the first phase of implementation of the NHSP in England*. Retrieved August 15, 2006, from <http://www.library.nhs.uk/SpecialistLibraries/download.aspx?resID=123519>
- Bodner-Johnson, B. (1985). Families that work for the hearing impaired child. *Volta Review*, 87, 131–137.
- Beyond newborn hearing screening: Infant and childhood hearing in science and clinical practice (NHS2006). (2006). Retrieved August 15, 2006, from <http://nhs2006.isib.cnr.it/>
- Calderon, R. (2000). Parental involvement in deaf children's education programs as a predictor of child's language, early reading and social-emotional development. *Journal of Deaf Studies and Deaf Education*, 5, 140–155.
- Calderon, R., & Greenberg, M. (1999). Stress and coping in hearing mothers of children with hearing loss: Factors affecting mother and child adjustment. *American Annals of the Deaf*, 144, 7–18.
- Calderon, R., & Greenberg, M. (2000). Challenges to parents and professionals in promoting socioemotional development in deaf children. In P. E. Spencer, C. Erting, & M. Marschark (Eds.), *The deaf child in the family and at school: Essays in honour of Kathryn P. Meadow-Orlans* (pp. 167–185). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Davis, A., Bamford, J., Wilson, I., Ramkalawan, T., Forshaw, M., & Wright, S. (1997). A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. *Health Technology Assessment*, 1(10), 1–177.
- DesGeorges, J. (2003). Family perceptions of early hearing, detection and intervention systems: Listening to and learning from families. *Mental Retardation Developmental Disability Research Review*, 9, 89–93.
- Gregory, S. (1976). *The deaf child and his family*. London: George Allen and Unwin.
- Gregory, S. (1999). *Cochlear implantation and the under 2's: Psychological and social implications*. Paper presented to the Nottingham Paediatric Implant Programme International Conference, Cochlear implantation in the under 2's: Research into Clinical Practice, Nottingham.
- Gregory, S. (2001, September). *Consensus on auditory implants*. Paper presented to the Ethical Aspects and Counselling Conference, Padova, Italy.
- Gregory, S., Bishop, J., Sheldon, L. (1995). *Deaf young people and their families*. Cambridge: Cambridge University Press.
- Janjua, F. (2005). Hearing impairment: Age at diagnosis, severity, and language outcomes. *Archives of Disease in Childhood*, 90, 1207.
- Kampfe, C. M. (1989). Parental reaction to a child's hearing impairment. *American Annals of the Deaf*, 134, 255–259.
- Kennedy, C. R., McCann, D. C., Campbell, M. J., Law, C. M., Mullee, M., Petrou, S., et al. (2006). Language ability after early detection of permanent child hearing impairment. *The New England Journal of Medicine*, 354, 2131–2141.
- Lederberg, A., & Golbach, T. (2002). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of Deaf Studies and Deaf Education*, 7, 330–345.
- Luterman, D. (1999). Counselling families with a hearing impaired child. *Otolaryngologic Clinics of North America*, 32, 1037–1050.
- Luterman, D. (2001). Closing remarks. In E. Kurtzer-White & D. Luterman (Eds.), *Early childhood deafness* (pp. 149–155). Baltimore (MD): York Press.
- Luterman, D. (in press, 2007). *Technology in early childhood deafness*. Paper presented at "Parenting in the cochlear implant era", Nottingham.
- Marschark, M. (1997). *Raising and educating a deaf child*. Oxford: Oxford University Press.
- Marschark, M. (2000). Education and development of deaf children—Or is it development and education. In P. E. Spencer, C. Erting, & M. Marschark (Eds.), *The deaf child in the family and at school: Essays in honour of Kathryn P. Meadow-Orlans* (pp. 167–185). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Marschark, M., Conversiono, C., & LaRock, D. (2006). Optimizing academic performance of deaf students: Access, opportunities, and outcomes. In D. F. Moores & D. S. Martin (Eds.), *Deaf learners: New developments in curriculum and instruction* (pp. 179–200). Washington, DC: Gallaudet University Press.
- McCracken, W., Young, A. M., & Tattersall, H. (in press, 2007). Universal newborn hearing screening—Parents' experiences of early audiological management. *Ear and Hearing*.
- Moeller, M. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, 106, e43.
- Moeller, M. (2001). Intervention and outcomes for young children who are deaf and hard of hearing and their families. In E. Kurtzer-White & D. Luterman (Eds.), *Early childhood deafness* (pp. 109–138). Baltimore (MD): York Press.

- Siegel, S. (2000). *Resolution of grief of parents with young children and hearing loss*. Unpublished manuscript, University of Colorado, Boulder, CO.
- Silverman, D. (2000). *Doing qualitative research: A practical handbook*. London: Sage.
- Stredler Brown, A. (2005). Family-centred intervention: Proven strategies to assure positive outcomes. In R. Seewald & J. Bamford (Eds.), *A sound foundation through early amplification 2004, proceedings of the Third International Conference* (pp. 185–196). Great Britain: Cambrian Printers Ltd.
- Stredler Brown, A., & Arehart, K.H. (1998). Universal newborn hearing screening: Impact on early intervention services. *Volta Review*, 100, 85–117.
- Tattersall, H., & Young, A. M. (2006). Deaf children identified through newborn hearing screening: Parents' experiences of the diagnostic process. *Child: Care, Health and Development*, 32, 33–45.
- Temple, B., & Young, A. M. (2004). Qualitative research and translation dilemmas. *Qualitative Research*, 4, 161–178.
- Thompson, D. C., McPhillips, H., Davis, R. L., Lieu, T. L., Homer, C. J., & Hefland, M. (2001). Universal newborn hearing screening: Summary of evidence. *Journal of the American Medical Association*, 286, 2000–2010.
- Wake, M., Poulakis, Z., Hughes, E. K., Carey-Sargeant, C., & Rickards, F. W. (2005). Hearing impairment: A population study of age at diagnosis, severity, and language outcomes at 7–8 years. *Archives of Disease in Childhood*, 90, 238–244.
- Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited. *American Journal of Orthopsychiatry*, 51, 63–70.
- Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education*, 8, 11–30.
- Yoshinaga-Itano, C., & de Uzategui, C. A. (2001). Early identification and social-emotional factors of children with hearing loss and children screened for hearing loss. In E. Kurtzer-White & D. Luteran (Eds.), *Early childhood deafness* (pp. 13–28). Baltimore (MD): York Press.
- Yoshinaga-Itano, C., Sedey, A., Coulter, D., & Mehl, A. L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrics*, 102, 1161–1171.
- Young, A. M. (1999). The impact of a cultural-linguistic model of deafness on hearing parents' adjustment to a deaf child. *Journal of Social Work Practice*, 13, 157–172.
- Young, A. M., & Tattersall, H. (2005a). Evaluative accounts of the process and practice of screening—Parents of true cases share their experiences. In R. C. Seewald & J. M. Bamford (Eds.), *A sound foundation through early amplification 2004, proceedings of the Third International Conference* (pp. 175–184). Great Britain: Cambrian Printers Ltd.
- Young, A. M., & Tattersall, H. (2005b). Parents' evaluative accounts of the process and practice of universal newborn hearing screening. *Journal of Deaf Studies and Deaf Education*, 10, 134–145.
- Young, A. M., Tattersall, H., Uus, K., Bamford, J., & McCracken, W. (2003). Universal newborn hearing screening: Issues in the design of a true case study. *Australian Journal of the Education of the Deaf*, 9, 5–10.
- Young, A. M., Tattersall, H., Uus, K., Bamford, J., & McCracken, W. (2004). To what extent do the characteristics of the object of evaluation influence the choice of epistemological framework? The case of newborn hearing screening. *Qualitative Health Research*, 14, 866–874.

Received June 16, 2006; revisions received December 19, 2006; accepted December 19, 2006.