Hearing mothers’ inceptions and perceptions of systems to detect congenital hearing loss in their infants and young children prior to the fitting of a cochlear implant.

Alison M Marchbank
Cert. Education (UK), Diploma in Education (NZ), Post Grad. Dip. Sp. Ed. (HI); B.Ed (Melb)

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Abstract

Effective hearing screening has long been a goal of public healthcare systems in order to prevent the effects that a late diagnosis of permanent hearing loss may have on the developing child. For most hearing families, who typically have no previous experience of deafness, a diagnosis of hearing loss in their baby or young child is an unexpected life event.

Two sets of data were collected. First, from a questionnaire designed to locate parents who wished to participate in the study and establish a timeline for their individual stories of events in the diagnostic process. Mothers completed the questionnaires. Two sample groups of mothers were identified, babies who were not screened at birth (non-NHSP), from the UK (n=6) and Australia (n=12) and babies who had their hearing screened before leaving hospital in Australia (n=6). A newborn hearing screen correctly identified deafness in three of the NHSP babies. Results revealed that mothers in the non-NHSP group were most likely to suspect their own child’s hearing problem and delays were evident before a diagnosis occurred. A second set of data was collected from all the mothers (n=24) who discussed their experiences of diagnosis and the time immediately after. A narrative approach to data collection allowed the mothers the freedom to foreground the experiences and events that were most important to them and they told their stories in personal ways. The data were collected at different times, starting at the period in the UK when the distraction test was the population screening tool of choice and then following the implementation of newborn hearing screening programmes in selected birth hospitals in Australia.

Most of these mothers were concerned about their child’s hearing before any routine hearing screen or developmental checking occurred. For these mothers the confirmation process was often lengthy and complex, especially if it was associated with otitis media (“glue ear”). Reassurance and “wait and see” were common professional responses to early concern. For the undetected babies in the NHSP group, mothers needed to raise their concern about hearing in ways similar to those mothers in the non-NHSP group, although much later.
Mothers, in general, expected that a hearing problem could be “fixed”. As they came to each consultation or hearing assessment event, there was an expectation for them to understand new vocabulary generated by different tests and technologies that was outside their experience. They reported that they often left test situations feeling confused after results were inadequately explained or wrongly interpreted. The findings reveal that diagnostic practitioners were constricted by the discourse of their own technology or pedagogy and were frequently unresponsive to a mother’s perspective of her child’s hearing problem. Exemplary professional practice is documented and relates to the quality of the relationship between a mother and a professional, rather than the discursive practice constructed by tools and technology.

This current phenomenological study complements recent research studies to suggest that the experiences of mothers could make a valuable contribution to future evaluations of newborn hearing screening programmes when taken together with measures of developmental gain.
Acknowledgements

I gratefully acknowledge all the hearing mothers of deaf children in the UK and Australia who shared their stories with me about what it was like to discover their child had a permanent hearing loss.

I would like to extend my sincere thanks to Dr Phil Bayliss, at the University of Exeter, who caringly guided me for my Master’s degree towards phenomenology and an interpretative approach to research study. He helped me to see the prism turning to reflect the many ways of seeing.

I wish to thank my panel of supervisors, Drs. Margaret Brown and Linda Byrnes who supported me patiently throughout my journey and continued to encourage me with my writing. I acknowledge the clear vision of Dr. Rod Fawns, who as my mentor, maintained his faith in me as a writer and what I wanted to say. The thoughtfulness of all his comments and the contribution of the members of his academic study group have truly enriched my journey.

I would like to thank my son, William, for his enduring assistance with databases, charts and spreadsheets and being my on call ‘help desk’ irrespective of time zones. To my daughters, Jo-Anne, Gillian and Philippa I extend a special thanks for their contribution to the completion of this work with their sustained interest, patience and abiding capacity to listen. Finally, to my friends, Joan, Ginta, Ian, Sam and Rob, thank you for your friendship and consistent support throughout the whole time I was writing this thesis.
Statement of Authorship/Originality

This is to certify that:

(i) The thesis comprises only my original work towards the PhD except where otherwise indicated

(ii) Due acknowledgement has been made in the text to all other material used

(iii) The thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices

Signature of Candidate
Dedication

To all the hearing mothers of deaf children.
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Chapter One: Introduction

Deafness is a complex phenomenon. For a hearing person, it is impossible to simulate what it means to be born deaf, as simply blocking out sound does not erase the memory of auditory experiences. Typically a child born with a severe or profound hearing loss will live in a family with hearing parents and be deprived of most auditory experiences until such time as the hearing loss is detected and he or she is fitted with an appropriate listening device. Kleinman (1988) and Rolland (1987) argue that a diagnosis of any condition disturbs family and social networks. McCubbin et al. (1980) assert that the degree to which families as a group make sense of what has happened influences how well they continue to function as a whole. How parents assign significance to the diagnosis, as an unexpected event, is important for parents’ adaptation to their new situation (Bodner-Johnson, 2001; Calderon & Greenberg, 1999; Frank, 2000; Freund & McQuire, 1995; Hall, 1996; Venters, 1981). The diagnosis of congenital deafness, however impacts on the development of communication and language that affects not only the child but his or her relationship with the whole family (Greenberg, 1983; Henderson & Hendershott, 1991; Luterman, 1987; Meadow & Meadow, 1971).

Historically, a realisation that a child may be deaf becomes evident only when the child failed to talk, so hearing loss was rarely detected at an age that ensured the best chance of intervention or treatment to prevent long lasting developmental delay. Typical of deaf children, poor communication, delays in speech and language were difficulties that attracted the attention of teachers or clerics wanting to teach them. In the nineteenth century, such were the numbers of deaf students requiring specialist education that large institutions existed in the USA, UK and Australia solely for their schooling and generally deaf students were taught in these segregated settings, isolated from their families.

From both developmental and learning perspectives, the importance of early diagnosis of hearing loss began to be recognised soon after the Second World War (Ewing & Ewing, 1944; Whetnall, 1956). A combination of medical and developmental perspectives informed a discourse of risk, which related to the long lasting consequences of undetected sensorineural hearing loss on the
developing child. As a consequence, there was a public health commitment to lower the age at which congenital hearing loss was identified.

In the mid to late 1970s, screening babies for hearing loss during the second half of the first year of life was incorporated into routine developmental monitoring and health checks. This test became known as the distraction test and in the UK health visitors conducted these tests and likewise child health nurses in Australia (Hitchens & Haggard, 1983; Robertson et al., 1995). The distraction test promised good results if it was delivered in optimal conditions and the test protocols adhered to. In the UK, prior to screening, written information was also distributed to mothers to encourage their observation of their child’s auditory responses and enhance their participation in an overall view of the child’s development, particularly hearing acuity.

Evaluation of the distraction test was conducted by a number of researchers (Mott & Edmund, 1994; Robertson et al., 1995). Studies focused on the rates of detection, age at diagnosis and the impact of the age of diagnosis on the academic outcomes of children with a hearing loss; in this way the distraction test was evaluated as a tool suitable for population screening and the detection of sensorineural hearing loss (Bamford, Uus, & Davis, 2005). Such studies used a positivist paradigm and emanated from a consistent concern about the late detection of congenital deafness. In the UK, efforts were made to increase the effectiveness of the test by redefining the guidelines for its conduct and delivery, re-training the health visitors and increasing the responsiveness of general practitioners and paediatricians to the impact of hearing loss (McCormick, 1983; Scanlon & Bamford, 1990). Yet in spite of these efforts, by 1990, the evidence was that the distraction test under-performed as a screening tool according to the rules for population screening practice (Wilson & Jungner, 1968) and deaf children were consistently identified in their second year of life or later (Bamford et al., 2005). These issues were not confined to the UK. For example in the state of Victoria, Russ et al. (2002), found also that the pass/fail criteria for a screen test were ill-defined and referral mechanisms were highly variable, leading to delays in diagnosis. Previously, in 1986, Bamford argued that there had been neither epidemiological study nor evaluation of the service needs of families. He foregrounded the haphazard ways in which audiology
services in the UK had developed according to “local convention or [to] the particular exigencies of local urgent needs” (p.175).

New technology became available to screen newborn babies deemed ‘at risk’ for hearing loss and provided the impetus for a move to screen the hearing of all newborn babies. In 2000, newborn hearing screening programmes in the UK and Australia were rolled out in targeted regions, at selected city hospitals and birthing units. Around this time, evidence emerged from the USA that outcomes for children were significantly improved if a child was identified early, fitted with hearing aids and their families engaged with intervention services (Appuzzo & Yoshinaga-Itano, 1995; Calderon & Naidu, 2000; Mayne, Yoshinaga-Itano, Sedey, & Carey, 1998; Yoshinaga-Itano, Coulter, & Thomson, 2001; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). However, these studies were often of limited scope and the global claims were generally viewed with scepticism. This was particularly the case with reference to the selection of participants, restricted sample sizes, and the types of intervention programmes utilised by families (Durieux-Smith, Fitzpatrick, & Whittingham, 2008; Kennedy & McCann, 2004; Thomson et al., 2001). Nevertheless, early results from newborn screening, early hearing aid fitting and habilitation were broadly encouraging and overall improved outcomes for deaf children were broadly anticipated (Watkin et al., 2007). It is also noteworthy that the evidence from these early studies revealed significant interplay between many micro-psycho-social variables for children and families during the stages of the confirmation process. An example of this is the child’s medical history, parental choice of communication modality (sign/oral/auditory verbal approaches) and the many ways in which families engaged with services, according to their own perspectives about deafness and fit with early intervention programmes.

In hermeneutics what is developed is a possibility of becoming and being for the person which is the manner of an understanding of himself or herself. Hermeneutic phenomenological questioning has in a particular manner placed in the question the one who questions with the one who is questioned and the questioner is hereafter also affected by the question. This inceptual thinking does not involve a stepwise process driven method aimed at solving a practical
Gregory (1991) and Luterman (1979) argue that the shock of the diagnosis of permanent hearing loss is, for many, a very personal, traumatic experience and the thrust of epidemiology and efficacy research concerning new technologies to detect hearing loss make no reference to primary carers. More than twenty five years ago, Hitchens and Haggard (1983) reported that the “objective of any improvement in screening for pre-lingual sensorineural deafness is a lowering of the mean age at ascertainment; a necessary, though not sufficient, step is a lowering of the mean age of referral” (p.74). As well as emphasising that the detection process involved several steps, the authors drew attention to the weaknesses in the referral links and technical skills of those making the diagnosis, and most importantly, the attention given to the perceptions of parents. This was consistent with the main complaint of parents, at the time, in respect to the late identification of their child’s hearing loss and the unwillingness of the medical profession to initially believe their suspicions or concern about their child’s hearing problem found by Watkin, Beckman and Baldwin (1995). Luterman (1979) and Gregory (1991), also detailed mothers’ stories of deep shock and grief at hearing the news that their child was deaf and the ways in which this affected their capacity to immediately understand information offered about sensorineural deafness as a permanent condition. Such information was believed to be helpful to families at this time.

It appears then that in the past, the views of parents have been significantly absent from evaluations of systems to diagnose hearing loss in young children. Only now, as newborn hearing screening programmes are defined as central to the new standard of care, which Roush (2000) argues is “good news” (p.56) for families, have parents begun to be seen as agents rather than patients of the services provided (American Academy of Pediatrics Task Force on Newborn and Infant Screening, 1999). Recent research, has for instance, called for the need for audiologic assessment services to become family-centred (Gravel & McCaughy, 2004). Such thinking is consistent with contemporary beliefs about early specialist childhood intervention practice that place families in a more central position. It is also increasingly common that literature defines exemplary
practice as family centred, family focused or friendly (Dunst, 1985; Dunst, Trivette, & Deal, 1988; Mahoney & Bella, 1998). Accordingly, it is timely that the views of families, and mothers in particular, begin to be taken into account with regard to the benefits of the provision of early intervention services. Families provide a valuable perspective of what it is like to engage with “the system” in ways that are personalised and informative from the primary care giver’s point of view. This, then, is the essence of this study.

Preliminary to the current research study, I collected data as part of a study for a Master’s degree at the University of Exeter in the UK. The thesis was not subsequently completed at that institution as the researcher moved to Australia. I was then admitted into the University of Melbourne where I converted the research to a PhD, in keeping with the University’s guidelines. In the preliminary study, the accounts of six mothers with profoundly deaf children were corroborated with professionals’ accounts of their practice and my observations of the stages of clinical procedures in the confirmation of hearing loss. This small study was the catalyst for the current research. It provided a connection to and a timely context in which to explore the intersection between the phasing out of distraction testing and the implementation of newborn hearing screening programmes in Australia. Through mothers’ accounts, the aim was to provide insight into what it was like for a hearing mother to discover and receive the news that her child has a profound permanent hearing loss.

At this point it is timely to consider the views of deaf mothers and the deaf community. It is generally accepted that a capitalised ‘D’ represents the the culturally deaf group. To be a member of the deaf culture you do not have to be deaf, e.g. hearing children with deaf parents. However, entry into a cultural minority group means you behave, use the language and share the beliefs of Deaf people (Padden, 1991). To be culturally deaf, the degree and type of hearing loss is not a condition for membership. Yet perceptions of deafness are embedded in common terminologies e.g. ‘hard of hearing’ (USA), partially hearing’ (UK) or hearing impaired (Australia) and may be viewed differently than ‘deaf’. Hearing perspectives of ‘deaf’ can imply difference, poor linguistic competence and speech intelligibility. Parenting a deaf child seems only to be a problem for hearing parents and is a uniquely different experience than that of
deaf parents. Throughout this study the term ‘deaf’ is used to signify severe to profound loss of hearing to preserve a hearing perspective on what it means for hearing parents who have a deaf child without any intended disrespect for the Deaf as a cultural group.

I have a complex personal perspective. Working in the early 1970s as a primary school teacher, migrant children from non-English speaking backgrounds were included in the classroom. Not all these children progressed and learnt English at the same rate; some said nothing. On closer investigation, in conversation with mothers and fathers, it soon emerged that they had difficulties in speaking their own language also. Mothers shared the concern about their children’s communication difficulties. They knew about their own children when theory and knowledge failed their teacher. This experience provided not only the springboard to train as a teacher of the deaf but enhanced a personal perspective about the value of working together with parents.

Taking a break from teaching, the birth of deaf child was both a great shock and unexpected event. As a mother, my baby’s difference compared to his siblings was more or less immediately obvious. He showed little reaction to sudden loud sounds and presented as a dull unresponsive child who was totally disinterested in his surroundings. His early babble and vocalisations sounded strange until he fell silent and his passiveness grew. For the author, mothering meant an all consuming passion to find out what was wrong as his siblings took a back seat and our lives were turned upside down. As a family, there was a shift in the expected course of life events when eleven months later our son’s profound deafness was diagnosed. Returning to work as a parent of a deaf child, heightened an awareness of other points of view as I became increasingly aware of my own. Frank (2000) argues that having standpoints are not optional, ‘the only difference is whether or not they are acknowledged” (p.356).

This unexpected event challenged my professional understanding about parents’ experiences and reaction to a diagnosis of hearing loss and a person’s need to group and re-group according to different social supports and changes to personal networks. Mead (1934) acknowledges this development as unifying not one single personality, but multiple personalities that function in different
communities or lifeworlds with a capacity to change according to the ways in which individuals are acknowledged. In posing a question about mothers’ experiences of the discovery of her child’s hearing loss, I recognised that other mothers’ experiences are the possible experiences of my own and that ‘phenomenology addresses any phenomenon as a possible human experience’ (van Manen 1990, p.58).

Phenomenology is an approach best suited to looking closely at the everyday experiences of people (van Manen, 1990). Taking a perspective from within the interpretative paradigm, the use of Heidegger’s hermeneutic phenomenological methodology encourages reflective and attentive practice to illuminate particular phenomena of interest. This research study presents the stories of three groups of hearing mothers and a retrospective look at their experiences of the diagnosis of profound deafness in their children over the last decade. Each group of mothers is precisely poised at three different points in time as detection techniques changed according to the advances in medical science and technological imperative. In group one, in the UK in 1999, the experiences of mothers who suspected their child’s hearing problem at a time when the distraction test was still in place are reported. In group two, in Australia 2008, a second group of mothers’ experiences of a time between the demise of the distraction test and the implementation of newborn hearing screening in some areas are reported. Finally, in group three, in Australia also in 2008, mothers’ experiences of newborn screening programmes are reported at the time when the programme was still in the early phases of targeted rollout.

This study does not set out to investigate the particular steps and stages and referral pathways of national screening programmes past and present. The researcher has instead attempted to enlarge the psychological paradigm traditionally used in this type of research to look beyond the institutional influences, responses and rules for practice that typically characterise clinical encounters. Thus, this study seeks to illuminate mothers’ experiences of finding out about deafness through stories of their clinical contact with practitioners and the texts derived from mothers’ accounts of social interaction in conversation with the researcher. Taking the mothers’ perspective, at any of the stages in the diagnostic process, their accounts revealed the social intention of each
professional person, through their discursive practice. These transcripts are the social substance of this research; in this respect, no causal meanings emerge to be explained through a particular theory or model. Rather, this research has instead sought to ascribe to people the skills necessary for appropriate conduct removed from hidden states or social forces, in ways that could, in the future, make a fundamental contribution to improving practice.
## Definitions of terms connected to the diagnostic process

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<td>ABR: Auditory Brainstem Response.</td>
<td>Electro-physical measurement of the inner ear to provide specific information about cochlea and auditory nerve function; component of battery of tests to identify hearing loss in babies.</td>
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<td>Audiogram.</td>
<td>A record of hearing assessment.</td>
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<td>Cochlear implant.</td>
<td>An array of electrodes, surgically introduced into the cochlea to replace ineffective hair cells, which transforms sound vibrations into electronic impulses that stimulate the auditory nerve.</td>
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<td>Deaf</td>
<td>The description of someone who is unable to detect sounds averaged across five frequencies, 250, 500, 1000, 2000 and 4000 Hertz at/or greater than 70 decibels in the better ear (British Society of Audiology, 1988)</td>
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<td>Health visitor (HV)</td>
<td>Name of Infant or child health nursing role (UK)</td>
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<tr>
<td>Child health nurse (MChN)</td>
<td>Name of Infant or child health nursing role (Australia)</td>
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<td>Distraction test.</td>
<td>Screening hearing using a series of frequency specific noise-makers to elicit a head turn response in babies mature enough to perform this task (approx. age 7 months).</td>
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<td>HVDT</td>
<td>Health Visitor Distraction Test; the name of the population hearing screening tool in UK.</td>
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<td>Early intervention.</td>
<td>Typically, an early childhood specialist programme for families with children with a special need(s).</td>
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<td>ENT/Ear nose and throat surgeon.</td>
<td>Specialist surgeon who manages conditions associated with the ear.</td>
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<td>Myringotomy</td>
<td>A surgical procedure for the treatment of OME</td>
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<td>Grommets</td>
<td>Ventilation tubes.</td>
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<td>Otoacoustic emissions (OAE)</td>
<td>Measurement of transient sounds (echoes) emitted by the cochlea to evaluate cochlea function; important component of newborn hearing screening test battery.</td>
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<td>Otitis media with effusion (OME)</td>
<td>Commonly known as ‘glue ear’ a condition associated with conductive hearing loss.</td>
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<td>Pressure test, typanograms</td>
<td>A measurement of mobility of the eardrum and to examine the capacity of the ossicles to conduct sound.</td>
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<td>Peripatetic or visiting teacher</td>
<td>In the UK context, a teacher of the deaf who visits the home from the education department</td>
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### Glossary of terms associated with the theoretical perspective

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<td><strong>Agency</strong></td>
<td>The state of being in action or of exerting power (The Concise Macquarie Dictionary, 1982) (p.33). A sociological model of agency which views a person in relation to the social world and thus s/he is constructed by it. Davies (1990) argues that agency is discursively constructed to make positions available to some and not to others.</td>
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<tr>
<td><strong>Ethogenics</strong></td>
<td>The study of the conventions of social practice characterised by the discursive production of meaning between people in conversation (Davies &amp; Harré, 1990). A study of the forced or deliberative positioning of persons in everyday conversations, settings and encounters.</td>
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<td><strong>Hermeneutics</strong></td>
<td>Used as an ontological approach to understanding; a continuous circular process of interpretation until a phenomenon becomes clear, related to and guided by a background of understanding (Gadamer, 1976b). This approach assumes a perspectival connection to the phenomenon of study.</td>
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<td><strong>Local moral order</strong></td>
<td>The ways in which a person behaves in relation to others’ expectations whilst conforming to what is appropriate in different social contexts (Cook, Moore and Steel, 2005). The interpersonal rules (grammars) that frame a social role in any given encounter to make actions intelligible and without which we could not participate in social interaction (van Langenove and Harré, 1999).</td>
</tr>
<tr>
<td><strong>Positioning</strong></td>
<td>Positioning is the discursive process whereby people are located on conversations as observably and subjectively coherent participants in jointly produced storylines (Davies &amp; Harré, 1990). A study of the dynamics of conversation where the necessary skills and abilities of a person are seen as enabling them to intentionally act and function responsively as a person according to the expectation of others (Cook, Moore &amp; Steel, 2005). Positioning places a self within recognisable categories of storylines for the purpose of understanding a person’s participation in social settings (Linehan &amp; McCarthy, 2000).</td>
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Typically, hearing parents do not expect to have a deaf baby, yet more than 90% of deaf infants are born to parents who have had little or no experience of deafness or children born with a permanent hearing loss (Feher-Prout, 1996; Hyde, 2005; Meadow, 1980; Shepherd & Galloway, 2003). A baby, with undetected hearing loss, born to hearing parents will develop in an environment where audition plays a key role in the critical period for first language acquisition (Lenneberg, 1967; Stern, 1985). These babies will experience less than optimal cognitive, communication and social development, with the potential for lasting effects when compared with their normally hearing peers (Durieux-Smith, Fitzpatrick, & Whittingham, 2008; Lederberg & Spencer, 2001; Menyuk, 1972; Pipp-Siegel, Sedey, VanLeeuwen, & Yoshinaga-Itano, 2003; Robinshaw, 1995; Schaefer & Lynch, 1980).

Congenital hearing loss is one of the more common birth abnormalities. Epidemiological studies estimate that the prevalence of a significant hearing loss present at birth occurs in 1.4-1.6 /1000 live births (American Academy of Pediatrics Task Force on Newborn and Infant Screening, 1999; Bamford, Uus, & Davis, 2005; Fortnum & Davis, 1997; Mehl & Thomson, 1998; Parving, 1991; Prieve & Stevens, 2000; Robinshaw, 1995; Upfold & Isepy, 1982). A third of these children will have a severe to profound loss of hearing that require specialist intervention (National Institute of Health, 1993; Northern & Downs, 1991; Samson-Fang, Simons-McCandless, & Shelton, 2000) and it is estimated that more than two thirds of these students are educated outside regular classrooms. Whilst advances in hearing aid technology and the availability of cochlear implants have contributed to improved outcomes for deaf children, in their rates of language development, age appropriate spoken language and comprehension skills when compared to normally hearing peers (Geers, Nicholas and Sedey, 2003; Svirsky et al., 2000), their overall performance continues to lag behind their hearing peers (Kennedy et al., 2006; Sarant, Holt, Dowell, & Rickards, 2009; Wake et al., 2005). The lifetime costs associated with the support and education of deaf students is believed to be in excess of...
Early detection and intervention are deemed to be a cost effective way of dealing with congenital hearing loss.

2.1 A pathology of hearing loss

There are two types of deafness, a sensorineural loss of hearing, which is permanent, and a conductive hearing loss that is almost always temporary. Sensorineural hearing loss accounts for an irreversible loss of auditory sensation because of a break in the sensori-neural chain. Unlike other congenital abnormalities it is not always obvious at birth. The majority of infants diagnosed present with no observable or remarkable features (Cone-Wesson et al., 2000; Davis et al., 1997; Durieux-Smith et al., 2008; Russ et al., 2003; Uus & Davies, 2000). Risk factors for deafness account for less than 40% of cases of diagnosed congenital deafness. They may be associated with family history, visible cranio-facial or head and neck deformities, low birth weight or prematurity, birth trauma and inter-uterine infection, e.g. Cytomegalovirus (CMV) (Chu et al., 2003; Elssmann, Matkin, & Sabo, 1987; Mauk, White, Mortenson, & Behrens, 1991; Uus & Bamford, 2006; Watkin, Baldwin and McErnery, 1991).

It is not unusual for parents to notice that young children cannot hear. Periods of reduced sensitivity to sound are common in early childhood and may be a result of a cold or otitis media with effusion (OME). Parents on the whole, are familiar with this condition where there is a build up of middle ear fluid behind the tympanic membrane (eardrum) (commonly called ‘glue ear’). OME is transient and often asymptomatic. It is treatable in chronic cases, although physicians’ views about treatment regimes may vary (Finkelstein et al, 2005; Roberts et al, 1991). Another form of deafness is conductive hearing loss, which affects the middle ear. This temporary or fluctuating loss of hearing is documented here because it often interferes or becomes confused with a permanent hearing loss (Russ et al., 2005). For instance an unexpected finding in a study conducted by Robertson et al. (1995) during an investigation into the late diagnosis of congenital hearing loss, was the numbers of children who needed to have grommets (myringotomy) during the diagnostic process. These researchers emphasised “the limitations of current audiological techniques in distinguishing between a mixed (sensorineural and conductive) hearing loss and a purely
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Conductive loss” (p.15). A child with an ongoing conductive condition may present with delayed language development or changes in communication behaviour (Hasenstab, 1987; Silva et al., 1982), which is a presentation not unlike a child with a severe sensorineural hearing loss.

2.2 **A diagnosis of hearing loss**

From a mother’s or a caregiver’s perspective, hearing loss is not visible and typically there are no distinguishing features of hearing loss. The diagnosis of hearing loss is an audiological construct that provides measurements of an individual’s ability to detect sound at different pitch (frequency) and loudness (intensity). The measurements are plotted against normal hearing, using an audiogram, to give a numeric representation of residual hearing. An ability to make use of residual hearing varies from person to person and is “determined by a complex interplay of hearing loss patterns, proper fit and prescription of hearing aids, and educational, psychological and social factors” (Meadow, 1980, p.6).

From a medical perspective, Good (1994) argued that medicine constructs its own objects. How a diagnosis of deafness is constructed for a young child reflects a combination of medical, audiologic and developmental perspectives, which, when combined, construct a discourse of risk (Navarro, 1995). Diagnosis is a medical acknowledgement of difference and the facts that characterise difference can be variable and subjective. Yet, they categorise and legitimise meanings that influence and sustain a need for “expert” direction (Fulcher, 1990).

2.3 **The impact of hearing loss on the developing child**

A human fetus of 26 weeks is sensitive to sound (Birholz & Benacerraf, 1983). In the first few days of life studies have demonstrated that hearing babies have a startle reflex in response to sudden loud sound; they can detect and respond to the pitch changes in speech (DeCasper & Fifer, 1980; DeCasper & Prescott, 1984; Sininger, Doyle, & Moore, 1999).

As a rule, children born with intact hearing systems acquire their first language with little or no difficulty through spontaneous and effortless interactions with a significant caregiver, usually the mother, who cares for them on a day-to-day
basis (Bloom, 1973; de Villiers & de Villiers, 1978; Halliday, 1978; Locke, 1995). It is generally accepted that the first few years of life are a critical period for spoken language development and that hearing is vital to understanding speech and developing oral language skills (Lenneberg, 1967; Menyuk, 1972; Rossetti, 1991; Ruben, 1997). In deaf babies, auditory sensation is weakened if not destroyed (Robinshaw, 1994). Evidence that undiagnosed or late detected hearing loss significantly affects a young child’s communication, language, literacy, social and emotional development is widely documented in the literature (Ballantyne, Martin, & Martin, 1993; Boothroyd, 1982; Carney & Moeller, 1998; Davis, 1974; Kennedy et al., 2006; Kretschmer & Kretschmer, 1978; Lederberg & Spencer, 2001; Paul & Quigley, 1994; Robinshaw, 1994; Schlesinger & Acree, 1984). Congenital deafness has traditionally been diagnosed late (National Institute of Health, 1993; Robertson et al., 1995).

Historically, outcomes for deaf children have been measured and then compared with the outcomes of their hearing peers. Typically, poor academic achievement and linguistic deficits have characterised the ways in which deaf children have been viewed. It is noteworthy that research data collected from psychological assessments show deaf children to be of equal intelligence with their hearing peers (Conrad, 1979; Furth, 1971), while measurements of their language ability in the early years illustrate, that at first, deaf children progress in similar ways to hearing children (Kretschmer & Kretschmer, 1978; Robinshaw, 1995). Nevertheless, deaf students have continued to leave school with reading ages approximately commensurate with year three grade levels (Allen, 1986; Holt, 1993; Marschark, 1997b). What emerged from past research designed to examine the academic performances of deaf children, was that, whilst there were many factors that influence poor outcomes, the most important seemed to be the delay in diagnosis (Shaw, Chandler, & Dale, 1978). Deaf children were on average, more than two years of age before they are diagnosed and consequently already at risk for language delay (Carney & Moeller, 1998; Cone-Wesson et al., 2000; Durieux-Smith et al., 2008; National Institute of Health, 1993; Russ et al., 2003; Tait, 1987).
2.4 The logic and ethics of medical screening

Screening is defined as the systematic application of a test or inquiry to a whole population to identify individuals at sufficient risk for a disorder that requires further investigation (Department of Health, 1997). The logic of screening populations for disease requires firstly, that a target group is clearly defined. Secondly, that the condition needs to be an important health problem and the natural history of the disease needs to be adequately understood (Wilson & Jungner, 1968). Thirdly, that the validity of screening tests has established their efficacy. In the latter respect, the test needs to be highly sensitive (identifies people with the condition), specific (excludes the majority of people without the condition) with a high predictive value (positive results indicate with a high degree of accuracy that the disorder is present) (Kennedy, 2000). Fourthly, that the condition cannot be identified by other clinical means and there must be conclusive evidence that knowing about the condition can significantly “alter the natural history of the disease for a significant proportion of those screened” (Cochrane & Holland, 1971, p.3). In the particular case of hearing loss, since the advent of new screening technology and the cochlear implant, it is argued that identification alone is neither sufficient (American Academy of Pediatrics Taskforce on Newborn and Infant Screening, 1999; DesGeorges, 2003; Vohr (2003a) or “ethically defensible” without habilitation and specialist intervention services (Hyde, 2005, S572). Logically, once the condition is detected and appropriate interventions are implemented it is assumed that the outcomes for individuals will be improved (Hyde, 2003; Vohr, 2003b), however, in a summary of the evidence Thomson et al., (2000) suggest that the longterm benefits remain uncertain. Armstrong (1995) argued that the rise of screening and health surveillance, circumvents the need for any patient to present with symptoms for professional interpretation, observing that whole populations may be objectified as having “factor(s)” or a potential for a future problem, which establishes a concept of risk.

It is no longer the symptom or the sign pointing tantalisingly at the hidden pathological truth of disease, but the risk factor opening up a space for future illness potential (p.400).
The value of medical screening has general public acceptance for early detection of diseases and conditions that present as a hazard or risk to an individual and it is held as reasonable to expect better outcomes with appropriate interventions. However, while the logic cause, early detection and treatment/habilitation, supports one ethical structure or grammar, there is another ethical grammar that attends to the agency of relations between the primary carer and the professional administering the screen test, interpreting the results and making a referral to intervention services.

2.5 Screening practices for the detection of hearing loss

The universal screening of babies for hearing loss is not a new initiative. In the UK since the Second World War, the need to detect deafness early has always been recognised (Bamford, Davies, & Stevens, 1998; Boothman & Orr, 1978; Ewing & Ewing, 1944; Haggard, 1992; National Deaf Children’s Society, 1994; Watkin, 1991; Whetnall, 1956). It has been the target of public health disease prevention programmes in the UK, USA, Europe and Australia. Over the years, ways and measures have been debated to encourage and inform policies committed to the early identification of hearing loss through population screening (Boothroyd, 1982; Davis, 1974; Effenbein, Hardin-Jones, & Davis, 1994; Health, 1993; Moeller, 2007; Robinshaw, 1994; Ruben, 1997).

2.5.1 Distraction testing

For over forty years, until around the late 1990s, the distraction test was the method of choice for the screening of young children for sensorineural hearing loss in UK and Australia (Bamford, Davies & Stevens, 1998; Russ et al., 2005). This test was developed by Ewing and Ewing in 1944. A distraction test is a behavioural test used with babies at seven or eight months of age by health visitors in the UK, known as the health visitor distraction test, (HVDT) and child health nurses in Australia. This age was chosen as, by eight months of age, the startle reflex present at birth, has been replaced by a head turn and a baby’s ability to locate to sound (Ewing & Ewing, 1944; McCormick, 1988; Whetnall & Fry, 1971). In addition, babies around this age are mature enough to ignore familiar loud sounds; stop crying and stir when sleeping lightly in response to a voice. Distraction testing involves babies being engaged with a toy, a sound
being made and, if the child hears it, looking up and turning to locate the sound source.

In 1978, Boothman and Orr noted that in some areas of the UK, routine screening using distraction techniques accounted for poor detection rates of deaf children. The authors found discrepancies in the numbers of identified children before school entry when checked against the numbers of diagnosed children in school. As a consequence they undertook a study to examine the test procedures. They found numerous sources of technical error in the conduct of the test including, arbitrary distances between the baby and the sound source, child familiarity with the noisemaker, observer error and parent default rates. Ewing and Ewing (1944) specified that only definite head turns were to be scored as a response, yet, Boothman and Orr noted wide variation in the ways this protocol was interpreted by health visitors. This was reflected in the percentage of babies who passed the test, which fell very far short of the 90% of the population who should pass using any screening tool (Holt, 1974). Although the need to justify the practice of universal screening was not in question, an implication of this study was to draw attention to the specificity of the distraction test, its properties and the technical skills needed for its effective delivery. Concern also arose about coverage and the erratic attendances of families particularly following a ‘fail’ screen result. Apparent failure of the health visitor distraction test (HVDT) to fulfil its objective encouraged professional discussion that sought to improve the mean age of detection of hearing loss (Brown, Watson, & Alberman, 1989; Haggard, 1990; Johnson & Ashurst, 1990; Latham & Haggard, 1980; Parving, 1985).

In the UK, in 1983, McCormick devised a number of strategies to improve detection rates. While maintaining the distraction test as a screening tool, he also sought to raise the awareness of parents to the signs and symptoms of hearing loss with the introduction of a checklist for hearing. He proposed to improve the technical delivery of the distraction test through peer reviews of test practice, health visitor re-training and professional development. Giving information sheets and offering mothers a checklist about permanent hearing loss was also trialled in the Trent health region in the UK to encourage mothers to report any concerns about hearing to health visitors. In this study, Hitchens
and Haggard (1983) found that giving mothers information could be a useful adjunct to screening programmes in poorly resourced areas. In addition, Hitchens and Haggard hypothesised that the addition of parental concern could be a valuable signpost when physicians needed to make a decision whether or not to refer children for audiologic assessment. The authors noted that:

The chief complaint of parents of late-ascertained children has been the unwillingness of medical personnel to believe their suspicions of deafness. The low incidence of profound deafness in general practitioners’ experience and the fact that the sequelae are of educational rather than medical concern perhaps explain the incredulity (p.74).

In 1990, Scanlon and Bamford (1990) published the results of a study undertaken in the early to mid 1980s to evaluate the changes made to the techniques in the delivery of the test items, the skill levels and training routines for health visitors as suggested by McCormick in 1983. Their results showed that the effect of these changes was an over-referral of babies with otitis media with effusion (OME) and the positive predictive value of the distraction test for sensorineural hearing loss remained much lower than that of 78.6% quoted by Haggard in 1986. Of equal concern was that referral meant “unacceptably” long waiting times, upwards of six months, due to the large numbers of children being referred not only as a result of the HVDT, but through other channels according to parental or medical concerns about a child’s health. Specifically, Scanlon and Bamford found that in their health district, West Berkshire, they were unable to replicate the results achieved by McCormick (1983) or Haggard (1986) in the Nottingham health region. In 1990, from a public health perspective, Haggard (1990), recognising that late detection of hearing loss was correctly viewed as serious failures of preventive child health services, questioned the cost effectiveness of the distraction test, when measured against its achievement in the early detection of congenital deafness.

2.5.2 Advances in technology: otoacoustic emissions (OAE) and automated brainstem response (ABR)

In the early part of the 1990s, advances in technology made it possible to screen the hearing of newborn babies using transient evoked otoacoustic emission
(OAE) and automated brain stem responses (ABR) (Kemp & Ryan, 1993). In the USA, in 1982 the Joint Committee on Infant Hearing issued a position statement recommending that babies known to be “at risk” for hearing loss be followed up with audiologic assessment to determine a baby’s hearing status. Initially the new screening technology was limited to screening the hearing of those babies with defined risk factors, and programmes became known either as “targeted” or “at risk” screening. Wood, Davis and McCormick (1997) defined risk according to four major factors. These were, first, a stay in a neonatal intensive care unit, second, a family history of congenital deafness, third, craniofacial deformity and fourth, maternal rubella. In 1990, the Joint Committee on Infant Hearing amended their 1982 position statement, firstly, to extend the “at risk” list of conditions and secondly to suggest a specific hearing screening protocol. This was followed in 1994, by a further amendment that endorsed the goal of universal hearing loss detection through support for research and development of technology suited to the early identification of all infant hearing loss. Whilst preserving a commitment to “at risk” screening, factors associated with parental concern and otitis media were also recognised through an acknowledgement of the adverse effects of all types of hearing loss on children, irrespective of when it occurs.

In the UK and Australia, “at risk” programmes were also operational at around the same time as in the USA. Typically, these programmes were called “two tier screening” because they represented a combined approach to hearing loss detection, exemplified by 1) the use of new OAE technology with newborn babies at risk for hearing loss and 2) distraction testing for older aged babies. Overall the goals were the same as in the USA, to reduce the median age of diagnosis, hearing aid fitting and families’ enrolment in specialist services (Russ et al., 2002).

In 1989, Scanlon and Bamford undertook a two year trial of the two-tiered approach, where the HVDT was discontinued. It was replaced with 1) the screening of all newborn babies ‘at risk’ for hearing loss and 2) referral for audiologic testing as a result of professional or parental concern. Two aspects of hearing screening practice, the increased focus and reliance on caregiver report regarding a child’s hearing and a public health campaign, were designed to raise
the public awareness of sensorineural hearing loss in babies and young children. Although a community nursing focus had always leaned towards caregiver report, a public health campaign to raise awareness about sensorineural deafness and a refocusing on parents’ concern about hearing was indicative of refreshed commitment to its early identification. No additional expenditure was envisaged as costs were estimated to be the same as the previous system.

McCormick (1990) acknowledged Scanlon and Bamford’s (1989) bold step in their revisions of the system and their stated intention to improve the referral system. However, he was sceptical of any hurried implementation of a trial two-tier system and cessation of the HVDT before any other alternative system was in place. Notwithstanding this perspective, McCormick argued that without a finely tuned dedicated system in place at the start of the trial, accurate data would be difficult to collect. He suggested rather that Scanlon and Bamford should question the unacceptable “current level of performance” (p.484) of the distraction test in their region when compared with the specificity and sensitivity of the distraction test in other regions. McCormick (1983; 1990) continued to consistently argue that the distraction test was an effective screening tool in skilled hands.

A study undertaken in Nottingham (Wood, Davis & McCormick, 1997) was designed to examine the impact of “at risk” or universal newborn hearing screening programmes on the health visitor distraction test over a ten year period 1984-1993. Results showed 19% of all children were diagnosed with hearing loss $\geq 50$dB as a result of targeted newborn hearing screening and 34% from HVDT. The number of referrals of children too young for the health visitor distraction test was stable. However, an unexpected result was a reduction in the performance of the distraction test. The authors explained this in two ways: first, that the health visitors had a “false sense of security” (p.59), knowing that babies ‘at risk’ for hearing loss had already been screened and detected and second, institutional and management structures reduced accountability and opportunity for refresher skills courses. These results pointed to an increasing role for targeted newborn screening, ongoing monitoring of the performance of the health visitor distraction test that included tester training and skill building.
Results from an Australian study revealed “at risk” screening to have a modest success (Russ et al., 2002). That is, there was both an increase in the numbers of infants with hearing loss >40dB detected and fitted with hearing aids before the age of six months and a decrease in the median age of diagnosis for children with a hearing loss in the severe category. However, the goal of confirmation of hearing loss, hearing aid fitting and engagement with services for all babies with hearing loss greater than a moderate degree was not met where newborn screening tests had correctly indicated the presence of a problem. This raised the question of the appropriateness of the definitions assigned to ‘at risk’ factors. Russ et al., posit that variable interpretations of these definitions affected the ways professionals framed the questions or indeed understood the answers contributed to the low rates of early diagnosis.

2.5.3 The inclusion and influence of parental concern

Many sources in the literature document the importance of taking into account the views of primary caregivers about their child’s ability to hear during hearing screening procedures (Barringer et al. 1993; Coplan, 1987; Elssmann et al., 1987; Mehl & Thomson, 1998; Rickards, Roberts, & Dennehy, 1993; Robertson et al., 1995). A study conducted by Shaw et al., (1978) found that parents experienced delays in referrals to audiology services despite their concerns about hearing. Coplan (1987) argued for the inclusion of parental concern in any referral decisions for audiological evaluation “because parents are usually at least 12 months ahead of the physician in recognizing hearing loss in their own children” (p.212). Findings from a study conducted by Rickards, Roberts and Dennehy (1993) revealed that parents’ concern alone resulted in children being referred to audiology services markedly later than children referred by a professional for other reasons.

Elssmann et al. (1987) conducted a study in Arizona to investigate the ages of children at diagnosis according to their birth histories. The study sample was divided into two categories which were children at high risk for hearing loss and children with no risk. Survey data revealed that, overall, 65% of parents with children in either category reported a concern about their child’s hearing to a physician. The results showed that there was no difference in the ages of
identification between the ‘high risk’ and ‘no risk’ groups if parents were given good advice when they raised concern. “Good advice” was defined as an appropriate referral, whilst “poor advice” was defined as “minimizing or dismissal of parents’ concerns” (p.16). Delays of 5-6 months were reported following “good advice” and 10-12 months if parents received “poor advice”. The authors concluded that any professional dealing with a parent’s concern about hearing could exert significant influence on the age of diagnosis.

Thompson and Thompson (1991) undertook a retrospective study of past and present parents enrolled in an Early Childhood Home Instruction Program for deaf children in Washington State, USA. Data were gathered to identify parental concern about their baby’s hearing, delays in diagnosis, access to services and the degree of support that parents received from professionals with whom they had had contact. Of 49 respondents, 48 parents were found to be the first to have suspected a hearing problem. This survey of parents revealed a delay between suspicion and diagnosis of approximately 8.9 months, although diagnosis occurred earlier when professionals paid attention to parents’ concerns. Yet parents reported a poor response by professionals to their initial concerns. ‘Wait and see’ was typical of comments made to the parents in this study and was consistent with the findings from a later study conducted in 1995 by Roberson et al., These researchers found that professionals falsely reassured parents who raised a concern about their child’s hearing, which resulted in delayed access to audiology services. Becker (1976) had previously drawn attention to the fact that parents generally were not reassured by professional comments when they raised a concern about a child’s hearing. Thompson and Thompson argued that when parents expressed a concern about a child’s hearing, a referral for audiologic assessment was appropriate for two reasons. First, if the child did have a hearing loss, then delay was minimised, and second, if the parents were hearing, “concerns about their child’s hearing status can be alleviated” (p.80).

Watkin, Balwin and Laoide (1990) undertook a study to investigate the role of parental suspicion in the detection of hearing loss. The health visitor distraction test was fundamental to the process to detect hearing loss in the UK at that time. Surprisingly, the results revealed that parental suspicion played only a small part in the total process, especially when the degree of impairment was slight.
Although parents were encouraged to report their concern as part of the overall routine of developmental checking, parents found recognition of a hearing problem a difficult task because symptoms of deafness presented in subtle ways during the early years. Whilst a research recommendation was to improve the efficacy of the distraction test, the results also drew attention to the reluctance of some mothers to return to audiology clinics even after their babies failed a distraction test. Robertson et al., (1995) reported research evidence that showed that some parents were similarly reluctant to accept a diagnosis while Watkin and Baldwin (1999) found that parents delayed in taking up appointments to fit hearing aids to identified children.

The views of parents were central to a retrospective study conducted by Watkin, Beckman and Baldwin (1995). They found that parents were increasingly concerned by the failure of distraction type hearing screening to detect congenital hearing loss. A questionnaire asked parents for their opinions on two issues: first, they were asked whether or not their child was diagnosed “at the right age” and second, whether they would have preferred their child to have been screened at birth with a diagnosis soon after. Parents could also record if they did not have an opinion either way. Qualitative data were collated. The majority of parents said they would have preferred an earlier screen and an earlier diagnosis. The researchers acknowledged the considerable insight of parents into the benefits of early diagnosis, not just from the point of view of earlier hearing aid fitting, but principally, with regard to mothers’ responses to their babies, e.g. “adapt to the child’s needs” or “would have stopped me thinking she was just being naughty and ignoring me”.

Harrison and Roush (1996) undertook a nationwide study in the USA to gain a better understanding of the delay in the stages between diagnosis, hearing aid fitting and the start of early intervention or habilitation. The results were reported in two groups according to risk factors for hearing loss. Harrison and Roush found substantial delays in the stages between parental suspicion and diagnosis, diagnosis and hearing fitting and hearing aid fitting and enrolment in an early intervention programmes. Parents of children with severe or profound deafness reported to have become concerned about the possibility of a hearing loss when their child was aged approximately eight months compared with other
parents with children with lesser degrees of hearing loss becoming concerned when their children were much older. Children with risk factors for hearing loss, where parents also suspected hearing loss, were diagnosed sooner. Qualitative evidence from parents regarding the nature of the delays revealed that third party complications, e.g. audiologists or a child’s health were factors contributing to the delays. The authors recommended that even if a child had health concerns, including otitis media, then this condition should not preclude the appropriate selection and fitting of hearing aids. They also strongly suggested that delays due to the need for “further audiologic assessment” were unacceptable as an excuse for late referrals to early intervention services. The results from this study were based solely on parental report and no clinical or medical records were available. However, despite the patterns of delay that emerged, the evidence suggested that the delays between the stages were indeed shorter according to severity of the hearing loss.

2.5.4 Making a case for universal newborn hearing screening

Otoacoustic emission technology offered improved specificity and sensitivity as a hearing screening tool. Used with automated auditory brainstem response testing, it was possible to complete an audiologic assessment and diagnosis of a baby by the time s/he was three months old. Evidence from studies emerged to show that ‘targeted’ or ‘at risk’ screening resulted in the detection of 40% or less babies with a sensorineural hearing loss (American Academy of Pediatrics Task Force on Newborn and Infant Screening, 1999; Durieux-Smith & Whittingham, 2000; Hyde, 2005; Russ et al., 2002) and there were campaigns to move beyond ‘at risk’ factors and extend hearing screening to all newborn babies.

In 1999, the American Academy of Pediatrics Taskforce on Newborn and Infant Screening reported that the average age of the detection of hearing loss, at the time, was about 14 months; “at risk” screening identified about 50% and that a reliance on professional or parental concern was unsuccessful. They concluded that before a universal approach to newborn hearing screening could be considered, other criteria needed to be satisfied. Any newborn hearing screening programme ideally would need to detect every baby with a hearing loss and be
cost effective. Specific interventions, with a demonstrated improvement in outcomes for deaf children, were required to be in place for babies and their families after detection to minimise the effect of hearing loss. The Taskforce on Newborn and Infant Screening suggested performance indicators which included, a coverage of 95% of the target population with a false-positive rate of ≥3%, a false negative rate of zero and a referral rate not to exceed 4% of the population.

The period moving from distraction testing, targeted at-risk or two tier approaches to hearing screening to a universal programme designed to screen all newborns was a time of challenge and debate. In the UK, before serious discussion started, Bamford (1986) had already proposed that an appraisal of the whole area of paediatric audiology was needed. He argued that the early identification of hearing loss was not sufficient without integrated specialist intervention services and follow up for families. Similarly, Haggard (1992) recognised the value of early detection of hearing loss, but argued that for the prevention of “auditory deprivation”, timely and appropriate “treatment” was the key. In this context, treatment was defined as the stages after diagnosis between habilitation and early childhood intervention services where distinct pathways connected families to services from the time their baby failed a hearing screen. Haggard proposed a universal standard for treatment that included trained staff working from children’s hearing assessment centres across the UK. He lamented the shortfall in skilled paediatric audiologists, experienced enough to provide the full range of audiometric testing to ensure timely hearing aid fitting, information and support to families.

In the USA, the poor detection rates of hearing loss in infants encouraged comparable academic and professional debate driven by audiologists (Downs, 1995; Mauk & White, 1995; White & Maxon, 1995). Yet, despite the advances in technology, the addition of hearing screening into universal newborn infant checking systems in the USA was slow and not without controversy (Bess & Paradise, 1994; Marschark, 1998; Mehl & Thomson, 1998). Bess and Paradise agreed that early detection of hearing loss was desirable. However, they argued that the specificity and predictive value of the OAE was problematic and resulted in many false positive results in the first 48 hours of life. The authors
suggested that the whole process to identify a hearing loss in a single child needed to be calculated if a true cost was to be formulated. They suggested that all the stages required to detect a hearing problem be included in the costing: These included screen recall, re-testing and referral for ABR and all the expenses associated with false positive results. Conversely, Marschark (1998) argued that the costs associated with early detection, given the sophisticated technology available, were an improper measure to restrict screening to ‘at risk’ populations rather than moving towards a universal approach. He questioned the opposition to any move towards universal newborn hearing screening, in the context of the broad impact and the well-documented deleterious effects of hearing loss on the developing child, drawn from years of research evidence from educators. He drew attention to National Institutes of Health consensus statements, which over the years, were

“…primary sources of detailed technical information… [that]..reflect the emergent view of a panel of thoughtful people who understand the complexity of the issues before them and have carefully examined and discussed a variety of data available to them (p.174).

White and Maxon (1995) argued that there was a genuine belief in the value of newborn hearing screening, evidenced by the numbers of hospitals that were prepared to implement the programme and the demonstration of professional commitment to newborn hearing screening. When compared with distraction testing or targeted ‘at risk’ screening, universal newborn hearing screening programmes emphasised efficacy, practicality and cost effectiveness. It was envisaged that deaf children would be identified sooner to allow for the timely fitting of listening devices and the earlier engagement of families with early childhood intervention services. White and Maxon calculated the costs of hearing screening to be one tenth of the costs associated with blood spot tests already in use with newborns. Drawing on the published data from The Rhode Island Hearing Assessment Project (White, Vohr, & Behrens, 1993), the researchers reported that the effectiveness of the screening conformed to the NIH guidelines (National Institute of Health, 1993) with respect to referral rates and specificity and surveys of professionals and parents had not reported any evidence of harm. Based on the research results available in 2001, the US
Preventive Services Task Force (USPSTF) concluded that the evidence was insufficient to recommend for or against routine screening or newborns for hearing loss.

Whilst few argued against the advantages of the earlier detection of a hearing loss to an individual child, establishing universal hearing screening programmes needed to take into account many issues. Firstly, successful implementation depended on epidemiology and a demonstrated correspondence between the incidence of sensorineural hearing loss, the return rates of detection (Young & Andrews, 2001) and its cost effectiveness, and secondly, on the use of scientifically sound screening technology with high specificity and predictive value. Thirdly, the skill, expertise and communication of professionals delivering the screening tests and results to parents emerged as a significant predictor of a meaningful experience (Fonseca et al., 1997; Luterman & Kurtzer-White, 1998; Russ et al., 2004; Tattersall & Young, 2006). Fourthly, the recognition of hearing screening as a process and potential for maternal anxiety with the recall of newborns who are later found to be hearing (Berg & Spivak, 1999; Magnuson & Hergils, 1999). In the literature, barriers to the implementation of universal hearing screening programmes were identified as difficulties in staffing to overcome and address the normal fluctuations in daily birth rates, early discharge policies of some hospitals and the need to avoid undue interference with mothers’ or hospital routines (Hall & Garner, 1988). Others noted that the maintenance of hearing screening programmes depended on cost effectiveness and certainty of funding streams (Johnson et al., 2006). In addition existing professionals faced not only the prospect of delivering accurate audiometric measurement and interpretation of results in babies younger than six months (Hyde, 2005), but a responsibility for a timely recall and retesting of babies. Also for consideration was the appropriate referral of families to services, many of which had pre-existing histories of complex entry protocols, structure and delivery (Young & Andrews, 2001), to ensure positive long-term outcomes for an affected child.

The Joint Committee on Infant Hearing was significantly revised in 2007 to address these challenges. Specifically changes were made in regard to issues of ‘well babies’ lost in the time between a screen fail and a follow up for their re-
screening and/or further auditory evaluation and differentiated screening protocols for babies who spent more than five days in a neo-natal intensive care unit (NICU). ‘Well-babies’ needed to be recalled for re-screening even if a fail was recorded for one ear. It was recommended for all NICU babies that screening and repeat screening be completed before discharge. The provision of services was also expanded to include babies with unilateral hearing loss and auditory neuropathy. For children with risk factors, hearing assessment should be customised to meet each individual need according to the nature of the risk factors and the likelihood of delayed onset hearing loss. The JCIH (2007) made specific mention of the need for paediatric audiologists and otolaryngologists working with newborns and young infants to have specialist skills. The statement revision also recognised the need for central referral points to ensure parents’ access to speciality services (non-medical) and the previous emphasis on “natural environments” (p.899) was expanded to mean both home based and centred based intervention options.

Moves towards a universal approach to newborn hearing screening progressed at different rates in the United States, the United Kingdom and Australia. Different factors influenced the rollout of programs. In the UK and Australia, a strong community child health service had been in place for many years (Watkin & Jerimiah, 1998; Russ et al., 2002). As a consequence for families, there was an established understanding of routine developmental checking grounded in maternal expectation of screening practices. This provided a solid foundation from which to explore new technology in response to a growing professional concern about distraction testing and ways to move forward to assess the hearing of babies in a cost effective manner (Davis et al., 1997).

In the United States, growing professional concern, inter-state collaboration between medical, audiological and education specialists and the JCIH were instrumental in exerting political pressure to improve hearing screening and assessment in newborn and young children. Consensus and/or position statements issued by American Academy of Pediatrics and American Speech and Language Association based on evidence derived from state demonstration projects were effective in raising the profile of infant hearing loss and the need to screen newborn babies.
Universal newborn hearing screening programs were differentially rolled out in the US, UK and Australia according to: 1) how the various challenges cited above were addressed in each country and/or by individual states (US and Australia) or regions (UK), and 2) how existing referral systems, structure and protocols influenced the process of hearing screening. In the USA, newborn hearing screen programmes were rolled out in 37 states (Vohr, 2003) in selected areas and hospitals from around the year 2000. In the UK, whilst a national programme was planned, initially selected health districts were targeted and the programme was rolled out slowly in an incremental way with distraction testing (HVDT) remaining in place. In Australia, The Western Australian Newborn Hearing Screening Programme was an important first step two years behind the USA and the UK, although the coverage attained represented less than half the live births for Western Australia (Wake, 2002). Over the subsequent two or three years the states of New South Wales, Victoria, South Australia and Queensland followed although implementation of screening programs was targeted to main birthing hospitals. Wake recognised the logistical and economic obstacles to the implementation of statewide hearing screening programmes in Australia. However, in reviewing the success of UNHS in the US State of Colorado and given the similarity between the birthrates in Victoria and Colorado, she argued against limiting the rollout of programmes to targeted or larger birthing hospitals and proposed a universal approach to newborn screening. Table 2.1 provides an overview of the historical context for the implementation of universal newborn hearing screening programmes.
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<th>UK</th>
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<tr>
<td>Years prior to 1984, community child health based distraction screening test for all babies 7-9mths of age (HVDT)</td>
<td>Years prior to 1985, community child health based distraction screening test for all babies 7-9mths of age.</td>
<td>Years prior to 1992, some hospitals in some states identify babies at risk for hearing loss.</td>
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<td>1984-1993: introduction of targeted neo-natal screening</td>
<td>1991: rollout of targeted newborn hearing screening for at risk infants in selected hospitals in some States</td>
<td>1982 Colorado Newborn Hearing Screening Project encouraged hospitals voluntarily to screen all newborns prior to discharge</td>
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<td>1993: NDCS sets specific targets for age of Identification of hearing loss/appropriate intervention</td>
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<td>1994 JCIH Goals for universal detection of hearing loss before 3 mths 1999: NIH endorses implementation of UNHS, sets targets 100% of all newborns</td>
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<td>1993-96: Wessex Controlled trial of UNHS; Conclusion: that the optimum screening strategy is universal neonatal screening supplemented by a targeted infant screening within 1 year for babies not screened at birth</td>
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<td>1997: Publication of the critical review, commission by the Department of Health of the role of neonatal hearing screening in the detection of congenital hearing impairment.</td>
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<td>2000: Phased introduction of UNHS with initial pilot scheme at 20 sites</td>
<td>2001 Australian Consensus Statement: resolution to introduce UNHS across all states and</td>
<td>2000: State-wide demonstration project (New York)</td>
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<td></td>
<td>2002-2003 implementation of UNHS programs throughout New South Wales, with implementation proceeding in Victoria, Australian Capital territory, South Australia and Queensland territories</td>
<td>2000: JCIH position statement and guidelines for the early hearing detection and intervention programs</td>
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<td>2000 UNHS mandated in 35 of 50 states with legislation for the remaining states pending (American Speech Language Hearing Association, 2000)</td>
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2.6 Measuring outcomes for deaf children identified by newborn hearing screening

Incorporated into the numerous proposals and campaigns for universal newborn hearing screening systems were recommendations for appropriate and timely intervention services for families following detection and confirmation (Joint Committee on Infant Hearing, 2007). This view recognised that early identification alone without follow up services was not sufficient, although the need for early intervention services was predicated on the arguments of linguistic risk and of parents needing help in communicating with their babies after diagnosis (Thompson et al., 2001). Thus it was generally accepted that families, given a choice, needed to engage with both medical and non-medical early childhood intervention services as a comprehensive system of care after diagnosis (Hyde, 2005; Moeller, 2000; Vohr, 2003; Yoshinaga-Itano, Coulter, & Thompson, 2001). Although considerable emphasis had been placed on systems to identify hearing loss, far less attention was given to referral linkages and the models of intervention services (Fitzpatrick et al., 2007). In general, at this time measuring outcomes were the preferred way to safeguard established programmes to ensure their funding or influence implementation of new projects. In this way, researchers hoped to provide an evidence base to ensure the maintenance of universal hearing screening programmes in order, “to better understand the complex relationships between interventions and outcomes” (Bamford, Uus, & Davis, 2005, p.123).

With the identification of predicative factors for improved language learning and demonstration of better educational results, earlier identification could continue to be justified in the face of arguments about cost effectiveness and the low incidence of significant hearing loss.

Several small studies, conducted using opportunistic or convenience samples of children drawn from specific intervention or hospital programmes, were used to evaluate language outcomes of children (Appuzzo & Yoshinaga-Itano, 1995; Moeller, 2000; Yoshinaga-Itano et al., 1998). Unfortunately these results were unable to be generalised to larger populations because of several factors. These included, severity of hearing loss, methods of detection, medical histories as a
determinant of risk categories, the ethics of intervention approaches, and the types of treatment strategies or therapies which were not always taken into account (Bamford et al., 2005; Thompson et al., 2001). Nevertheless, some findings were encouraging. Evidence from research conducted by Moeller (2000) strongly suggested that family involvement was a key factor in improved outcomes attained by some children, which foreground the importance of the participation of families in a child’s language development. Watkin et al. (2007) reported similar findings to suggest that parent participation possibly led to improved outcomes.

The first population controlled trial for the identification of newborns with a hearing loss was undertaken by the Wessex Universal Neonatal Hearing Screening Trial Group between 1993 and 1996. This report recommended that the optimum screening strategy was universal neonatal screening supplemented by targeted infant screening at one year of age whether the child had been screened or not. This conclusion was similar to the recommendation of the NIH (1993). This study contributed powerful evidence to the debate, moving beyond the uncontrolled descriptive studies previously documented in this review.

Wake et al. (2004) argued the need for contemporary high-quality population surveys to demonstrate sustained outcomes for children with a range of hearing loss. The authors claimed that existing research was often flawed and outdated, relying on an over-representation of children in the severe or profound categories of hearing loss and descriptive reports from teachers. They undertook a population based study designed to overcome some of these flaws, particularly with reference to sample selection, access to and attendance at services and choice of communication/early intervention approach. Accordingly, Wake et al. undertook their study at the population level, to evaluate outcomes for children between the ages of seven and eight years, across the range of mild to profound congenital hearing loss. The results revealed that after two or four years of schooling, deaf and hearing-impaired children showed major deficits in all areas of language, social emotional and behavioural domains, despite timely amplification and prompt enrolment in an early childhood intervention programme. From a parent perspective, 82% of parents reported that they had developmental concerns. Teachers equally reported concerns about behaviour.
The researchers concluded that these results challenged the findings from previous studies with respect to the maintenance of apparent early gains as a result of newborn hearing screening and early detection. They also highlight the continuous disadvantages experienced by children with hearing loss and most noteworthy, the findings revealed that early identification, habilitation and early inclusion into specialist early childhood programmes seem not to be sufficient.

These research findings prompted a letter of response to the British Medical Journal from Janjua (2005), who defined the area of severe and profound deafness research as a “real minefield” given its low incidence and the numerous variables that needed to be taken into consideration when conducting outcome research. Janjua argued that the inclusion of a mild to moderate and severe hearing loss was enough to skew the results, as severity of hearing loss alone outweighed other controllable variables. As a consequence, the writer argued that the publication of these research findings was unhelpful and misleading at a time when some newborn hearing screening programmes were still under consideration or in a pre-implementation phase. Other research evidence confirmed some of the ideas expressed in Janjua’s letter, (Calderon, Bargones, & Sidman, 1998; Sarant et al., 2009) emphasising the variability that exists within the population who have a hearing loss.

Eisenberg et al. (2007) also argued for a more rigorous approach to sample size if data was to achieve “adequate statistical power” rather than small-scale studies with children identified via clinical referral sources. In short, the authors recommended either the development of sensitive screening markers to be applied to large population studies or the use of existing epidemiological child health studies, where hearing screening programmes were already in place. They also advocated the use of common assessment protocols and measures comparable to those used in other child health studies.

Nelson, Bougatsos & Nygren, (2008) undertook a review of the evidence of outcomes for children detected at birth through universal newborn hearing screening programmes. The researchers focused on three key questions. (1) Among infants identified through universal newborn hearing screening, who were not targeted as ‘at risk’ for hearing loss, did initiating intervention before the age of 6 months improve language and communication outcomes? (2)
Compared with targeted screening, did universal hearing screening increase the chance that intervention started before 6 months of age improve the outcomes for babies at high or average risk for hearing loss? (3) What are the adverse effects of screening and early treatment? This systematic review of the evidence suggested that at 8 years of age children identified through a universal hearing screening programme had better language outcomes at school age than those not screened or identified using different methods.

In spite of these conceptual difficulties, research studies concerning universal newborn hearing screening after 2000 continued to focus on demonstrating developmental gain (Kennedy et al 2006; Stredler Brown, 2005; Wake et al. 2005) with benefits measured as communication and linguistic outcomes. Toblin and Hebbeler (2007) provided an overview of research approaches used to examine outcomes for children with hearing loss. They identified the challenges associated with studies calculated to look at the impact of specific treatments or intervention variables on populations of deaf children. Compared to the general population, samples of children with hearing loss alone are relatively small. Yet the inclusion of deaf children with additional needs had the potential to offer very different outcomes not withstanding the challenges of an increased sample size. The authors described both simple and complex conceptual frameworks e.g. whether or not a child received a specific intervention therapy, or more involved frameworks to determine the impact of the age at which the intervention started, the period of time delivered and the impact of the qualifications and/or experience of the practitioner. Importantly, the authors argued that any conceptual framework needed to clearly identify the “critical features that will adequately capture the variations in receipt of the services or programs that are hypothesized to be related to the differences in child outcomes” (p.723). Acknowledging the variations in child outcomes research depends on child characteristics, such as race, ethnicity and gender, the variations in child treatments and therapy and understanding their impact on the family.

What consistently emerged from the literature was the importance of the roles of parents and the impact of a deaf child on the family (de Georges, 2003; Luterman, 2001; Young & Andrews, 2001) as well as the criteria that parents
use to appraise their diagnostic experiences (Tattersall & Young, 2005). Young et al., (2004) argued for the benefit of a qualitative approach in an overall evaluation health service delivery. Of necessity, the researchers advanced the centrality of inductive methodologies when seeking to illuminate beyond what was thought to be known to discover what needed to be known for the effective appraisal of newborn hearing screening programme. Whilst much of the evidence from previous research studies indicated that early detection was best and informed technological imperative, programme implementation and funding sources, what was missing was how parents’ own orientation and worldviews affected their meaning making practices in their everyday lives.

In summary, traditional research designs sought to demonstrate the benefits of newborn hearing screening through measures concerned with hearing aid fitting/cochlear implant surgery, language and communication development and parents’ engagement with specialist early intervention support service. As universal newborn hearing screening programmes were rolled out, a new dynamic emerged to be investigated, the lived experience of hearing parents of the process according to their personal values and belief systems (Young, 2002).

2.7 Intervention, parent support and early childhood specialist programmes

As a rule, the confirmation of a medical condition is followed by a treatment. In the case of hearing loss in babies and young children treatment, help and support has typically been known auditory management and specialist early intervention. This is particularly true of newborns diagnosed with a hearing loss (McCracken, Young & Tattersall. 2008; Sjoblad, Harrison & Roush, 2001). Now, parents with very early identified children are dealing with the prospect of further audiological testing, the fitting of hearing aids to a baby and coming to terms with the impact of deafness in a context of everyday family life with a new baby (Davies, Reeve, Hind & Bamford, 2001). Audiological management and parents’ engagement with clinical professionals is a first stage and part of the screening process (Young & Andrews 2001), in the overall intervention practice with deaf babies and young children.

The second stage is a family’s engagement with early childhood education programmes and specialist support. In 1985, Dunst argued that any notions of
an early intervention programme merely being to help parents was simplistic. Around this time, changes were made to the ways professionals helped families and their relationships with mothers or caregivers became of primary importance, in contrast to previous intensive therapy driven or child-centred approaches designed to address delays in language learning and communication development. In the late 1980s, according to Dunst, Trivette, and Deal (1988), a partnership approach with parents became the preferred way to inter-relate with families and constructed a different view of family involvement with their child’s learning. A partnership approach offered more opportunity for parents to make decisions on behalf of their deaf children. These changes, whilst maintaining a professional intention to help families and be supportive, demonstrated a different type of commitment from early childhood intervention agencies. That is, intervention practice focused on the support of families according to their particular strengths rather than advancing a professional view of the needs the deaf child, their caregiver or family situation.

Murphy et al., (1995) argued that even with the change of professional approaches to families, the delivery of services needed to be conducted in such a way that families’ achievement within a framework of goals could be measured (Bailey et al., 1998). A finding from a study conducted by Murphy et al. in 1995, was that most families did not know what to expect from intervention professionals. When practitioners presented themselves as “non-judgmental, amicably curious friends of the parents, the family [will] extend its boundaries and perceive early interventionists’ interest as appropriate and supportive” (p.218). Principles that reflected the aim of meeting the needs of the whole family differentiated from those that were oriented to the needs of the child, came to be known as ‘family centred’ or ‘family focused’.

Typical of intervention practice for hearing parents of deaf babies and young children is the giving of information after diagnosis (Eleweke, Gilbert, Bays, & Austin, 2008; Gravel & McCaughy, 2004; Mitchell & Sloper, 2002; Young, Jones, Starmer, & Sutherland, 2005). That parents may also require support is a premise that is widely accepted today and arose from a notion that parents need to adapt to the loss of a child they thought they had and accommodate to their child’s changed circumstances or learning potential (Bodner-Johnson, 1986;
Carpenter, 1998; Dunst et al., 1988; Watson, 1997). Bodner-Johnson (1985) discussed the role of a family’s innate resources as a key factor in predicting outcomes for hearing impaired and deaf pre-adolescents. Families who viewed deafness as a personal characteristic, accepted individual differences and coped with hearing loss as a series of life stages that ranged from difficult to less difficult, demonstrated positive adaptation and coping skills (Bruder & Nikitas, 1992; Carney & Moeller, 1998; Fallon & Harris, 1991; Luterman & Ross, 1991).

As already reported by Calderon et al. (1998), families have a critical role in the development of their child and their involvement continues to be an important variable when predicting or measuring outcomes for deaf children (Calderon, 2000; Gravel & McCaughy, 2004). Today, the development of programmes for the early detection of congenital hearing loss are predicated on how early diagnosis translates into improved developmental outcomes (Fitzpatrick et al., 2007; Yoshinaga-Itano, Coulter, & Thomson, 2001) which, by default, must include the practice of professionals, their encounters with parents and their deaf children.

How families enrol with specialist intervention or habilitation services with their newly diagnosed deaf baby is a final stage in the whole of hearing loss detection process and its associated specialist intervention services. Delays in families’ engagement with specialist services, differences in early intervention philosophy, choices of listening devices and approaches to language and communication and cultural and linguistic diversity are characteristic of some of the many variables for consideration in efficacy research of the part played by support services for families with young deaf children.

Central to a medical diagnosis is the clinical relationship and Mechanic and Meyer (2000) argue the trust that individuals have with their health professional is the way that

“…..individuals relate to one another on the assumptions that people generally are who they purport to be, will act in accordance with generally understood norms of behaviour and will meet their role expectations (p.657)
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The ways in which patients connect with clinicians to discuss the facts of a problem and start conversations about the ‘thing’ that they (or their child) have is pivotal to starting treatment regimes and intervention relationships (May, Dowrick, & Richardson, 1996). Just as pass or fail results and audiologic measurement connect professionals in a joint understanding of a diagnosis of deafness on the one hand, it could be said that the stories of diagnosis connect mothers of deaf children to one another.

2.8 Reactions to a diagnosis of deafness

For many, a reaction to the permanence of deafness can be with a sense of deep shock and disbelief (Allen & Allen, 1979; Luterman, 1979). Luterman said that it was not an uncommon occurrence for parents to have an expectation that a doctor can repair the ear or that treatment is available to “fix up” the hearing. A diagnosis of congenital hearing loss has variously been described as intensely stressful and confusing, particularly the time it takes for parents to adapt to the shock of the diagnosis (Brown et al., 2006; Calderon & Greenberg, 1999; Freeman, Dieterich, & Rak, 2002; Gregory, 1976; Kampfe, 1989; Meadow-Orlans, 1994; Spencer, 2000).

Luterman (1984) stated that the state of shock may vary in the time it lasts and can affect the ways in which parents are able to understand or remember information about the condition. Guilt, blame and anger are also typical reactions to diagnosis (Mindel & Feldman, 1987). Schontz (1965) referred to the ways in which parents recognise the deafness on the one hand yet deny its permanence on the other. Luterman (1985) described in detail how parents might use denial to gain time to recover from the shock and gain time to understand the impact of deafness. Luterman also described the responses of some mothers to a child’s deafness as a “grief” reaction similar to that experienced following bereavement and loss.

Kampfe et al., (1993) termed adaptation ‘recognition’ as it was more coherent with the permanence of the condition. Whatever parents’ reactions, Henderson & Hendershott, (1991) assert that a baby with a confirmed hearing loss is primarily a family member and as such, the deafness does not lie simply as a
condition within the child, but the diagnosis changes “the sense of equilibrium in the lives of families” (Fitzpatrick, et al., 2007, p.105).

2.8.1 Models of grief

The literature suggests two theoretical perspectives on grief; one that is time bound proposed by Kubler Ross (1970) and the other a model of perpetual grief, punctuated by periods of remission and intense sorrow (Murgatroyd & Woolfe, 1993; Olshansky, 1962; Tinlin, 1996). In the 1980s, professional support frequently used the sequential stages of Kubler-Ross’ model of grief and loss to assess and consider a mother’s adjustment to having a deaf child. Whilst this stage approach seemed useful to assess how mothers were coping with the impact of the diagnosis, this model assumed that each mother followed the same route. In a review of the literature conducted by Lowes and Lyne (2000) with parents with children diagnosed with childhood Type1 diabetes, findings suggested that parental responses to the diagnosis were not uniform. Whilst some parents experienced a time bound grief, others had recurring periods of acute sorrow at times of extra stress or transition. For these parents, acceptance and resolution seemed to be permanently on hold.

Bruce, Schultz and Smyrnios (1996) examined the accounts of mothers and fathers whose children were diagnosed with intellectual disability. Significantly, a theme of ‘non-finite loss’ emerged to exemplify parents’ experiences of coping with a diagnosis and having a child with a disability. ‘Non-finite’ loss marked parents’ disconnection from the mainstream often with “incessant triggers in the environment that accentuate or reactivate the discrepancies and fears” (p.10). The researchers also found that whilst the extent of the grief was highly individual, different themes emerged which highlight the diverse ways in which parents were affected and influenced how they managed.

These findings revealed a range of mothers’ experiences and the individual ways they responded to a diagnosis, which have a good fit with both phenomenological and developmental lifespan perspectives (Vondra & Belsky, 1993). Importantly, research studies that document parents’ experiences may serve to enhance professional views of how parents adapt, interpret and
recognize the meanings of their child’s condition and provide a perspective, which could both inform and enhance professional practice.

2.9 **An ecology of relationships: mothers, babies and primary health-care practice**

A new baby arouses various feelings in a parent. For a mother these feelings are commonly those of belongingness and attachment that is “nature’s way” to ensure appropriate care and nurturing (Leigh, 1987, p.11). Bowlby (1965) developed his theory of attachment that supports a view that relational attachment was necessary for a child’s optimal functioning. In her appraisal of the legacy of Bowlby’s work, Bretherton (1997) restated his assertion that a close continuous relationship with a mother, “or permanent mother substitute” (p.34) was fundamental to a child’s mental health and emotional security. Attachment theory also highlighted a relational connection to context and environment and marked a departure from the creation of an individual’s inner life, which characterised psychoanalytical thinking (Bretherton, 1992). In particular, a view of what it means to be a person is a capacity to form relationships with other persons.

Working from a view of a person as a historical and culturally located being, Thayer-Bacon (2003) argued that people learn about themselves through the reflections of others.

…thus when we begin to interact with others not like us, we begin with an assumption that others are like us, not even realizing the concept of difference. We become aware of our differences through interactions with others, through our efforts to establish common meanings so that we can communicate and relate to each other (p.251).

This is a view similar to that advanced by Giddens (1991), who discussed people’s view of themselves, their perspective, as a continual reflection and revision of their own biographies. In preference to a focus on personal characteristics, social behaviour or personality traits, this view centres on the ways an individual sees him or herself mirrored through the reactions of others and the extent to which personal narratives are sustained through regular interaction with others. That the development of a human being relies on interpersonal relations is drawn from the work of Vygotsky (1978). Within any
group, the transference of skills, either by words or other signs, is closely tied to the assignment and appropriations of rights and duties and how they are distributed according to the order of influence of the members of the group.

Harré (2004) explored the notion of ‘personhood’ through a view of each person having a multiplicity of selves. He identified four main aspects of personhood: the embodied self (unity and continuity of a person’s viewpoint and action in the material world over space and time); the autobiographical self (a personal perception of being hero or heroine in stories); a social self in encounters with others (the personal qualities that are displayed during interactions); and the self concept of self (the beliefs that people have about themselves). From this perspective a person is ever evolving according to the dynamic aspects of interaction and the complexity of his or her social encounters.

Mothers are influenced by their own culture and historicity; they care for children in environments constructed according to their own experiences. A view of the mother as a person, in a variety of social situations, cannot be easily seen when determined by the restrictive constraints of a ‘mothering’ role. How a hearing mother experiences her child’s deafness involves her personal perspectives about child development, child health and difference, and her relatedness to systems expected to care about mothers and their babies.

Mothers’ connections to primary health care and community nursing systems have been channelled and sanctioned over many years by welfare policies. A study undertaken by Lewis (1980) identified a core belief, which has flourished since the end of the Second World War, that maternal education was the key to improving child health and child-rearing practice. In the 1950s, a medical imperative introduced developmental surveillance and positioned mothers to rely more on science and the knowledge of experts. Articles appeared in woman’s pages in journals and magazines written by physicians who encouraged mothers to read more and ask for expert help with childrearing (Apple, 1995). Ideas that originated from science encouraged professional assessment of mothers and babies and routine intervention became standard health care practice (Hall, 1996). Welfare policies promoted views about children, mothers or families, which not only conformed to a norm and ideals.
acceptable to the state, but also met disease prevention and health promotion targets. Checking for developmental problems included screening for hearing loss (Hall, 1996).

One way of looking at systems of relationships to examine the phenomenon of what it means for a hearing mother to discover her child is deaf is through the use of Bronfenbrenner’s ecological model (Bronfenbrenner, 1979). Bronfenbrenner conceptualised development as a relational interplay between a person and the environment. This model emphasised human inter-relatedness that was represented as a nested system of environments, starting with face-to-face settings, known as a microsystem, enclosed within overarching exo- and macrosystems. Each macrosystem contains its own exo- and microsystems and refer to institutions e.g. medicine, education, policies, laws and rules. Bronfenbrenner’s model is adapted in Figure 2.1 to illustrate the influences of different health care environments (systems) on a mother and her baby. As a theoretical lens, it is possible to locate sources of influence and the likely social situations convened at the intersections for mother and her baby. Moreover, it may be possible to identify factors external to the home that combine to influence mothers and their roles to construct their relationships according to rules that society tacitly dictates how mothers should be (Lynch, 2007).
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Figure 2.1 An ecological model, according to Bronfenbrenner (1978) of the influence of interaction among a number of overlapping ecosystems for mothers and babies where hearing loss presents as a problem.

2.10 The agency of intervention

The basic tenets of Bowlby’s attachment theory concern the nature of a child’s tie to his or her mother (Bretherton, 1992). Bowlby proposed that a child has a number of component instinctual responses that tie him/her to the mother that go beyond psychoanalytical explanation. Component responses e.g. sucking and clinging and signaling behaviours, e.g. smiling and crying, mature independently in the first year of life with a result that the baby becomes
focused on the mother. In her review of the results of the academic collaboration between Mary Ainsworth and John Bowlby, Bretherton (1992) highlights individual differences as mothers’ particular sensitivities and intuitive responses to their babies’ signaling and social cues. Drawing on Bowlby’s groundwork regarding a mother’s social sensitivities to her baby, foregrounds a notion of a mother having a personal expectation of her relationship with her baby and how it will develop. A mother’s early concern about her baby’s responses is most likely to represent a disturbance to this expectation.

Before newborn hearing screening programmes, the system for routine infant checking included distraction testing. Mothers, purportedly, were encouraged to participate in this checking routine by monitoring their own babies’ responses to sound and communication development (Watkin et al., 1990). Since the implementation of newborn hearing screening there has been a paradigm shift in the process to detect hearing loss. No longer are caregivers’ concerns contributing factors to clinical decisions about a referral to audiology services, but rather, results from a hearing screening tools alone inform referral decisions with the mother being secondary to that process (Luterman & Kurtzer-White, 1999; Roush, 2000).

As Bronfenbrenner’s (1978) model suggests, the agency of intervention for mothers after she has identified a concern about hearing can be characterised by a sequence of social encounters. As a rule, confirmation of a medical condition is followed by a proposal for treatment. The argument for this study is that medical intervention is not simply a treatment or therapy. It is a practice discipline that involves important relationships between people where recognisable patterns of behaviour emerge through institutionalised language embedded in their activity. This activity is ethogenic in terms of this research that takes into account the local moral order of screening technologies, audiologic assessment and intervention practices; it is not something inevitable of causal necessity, but rather, people seem to act responsively in accordance to the expectations of others (Cook, Moore & Steel, 2005).

Theories about what constitutes the risk of late diagnosed or undiagnosed deafness drives the technological imperative for hearing loss screening and
testing. From a pragmatist point of view, James (1948) suggested of science that theories are approximations, which “are made true by events,” (Hartrick-Doane & Varcoe, 2005, p.82). Diagnosis, intervention and habilitation practices are the activities of people and hearing test results structure conversations with primary caregivers in a social context that represent a theoretical orientation according to the discursive elements or grammars that frame their conversations.

Davies and Harré (1990) defined discursive practice as the way people actively produce meaning around a specific topic according to the social arrangements of the people who co-construct it. Following the lead of Wittgenstein (1953), who asserted that language and reality were bound together, Harré (2002) argued that ontologies are in effect grammars, which demarcate boundaries for some purpose or other, in this case, permanent childhood deafness, its confirmation and intervention.

The ethogenic approach is founded on the belief that each person tends to be how language, culture and knowledge, either implicit or explicit, dictate how he or she should be. Each particular social world has its own social objects to be understood according to the ways they are used. Harré (2002) further developed this view to suggest that the existence of certain substantives (nouns) come to have meaning only in the ways they require a social context to complete their sense, which reflects the activity between two people. A speech-action becomes a determinate speech-act only in so far as it is assimilated as such by participants. Accordingly, as Davies and Harré (1990) argued, “actual conversations between particular people on particular occasions” (p.44), construct specific discourses each with their own objects and social purpose. The conversations between agents here, mothers and practitioners, in the context of confirming a child’s permanent hearing loss and engagement with specialist services, disclose the discursive positions of each agent and the meanings that they attribute during each particular encounter.

As new events happen, mothers’ conversations constitute the speakers according to their roles to be interpreted in those terms (Davies & Harré, 1990). As a mother moves towards objects in others’ worlds that challenge her personal views, perspectives are reconsidered and renegotiated through
discursive practices that position the speakers and hearers in certain ways. Positioning is a sensitising concept for analysing the semiotic intentions in exploration of any social episode, “the relations between people and their conversations” (p.52). Harré (2004) represents his analytic framework schematically in a mutually determinate triad illustrated in Figure 2.2 and “challenges to the way an episode is unfolding can be directed to any one of the three aspects” (p.7).

Figure 2.2 Positioning Triangle (Harré, 2004).

Harré (1991) argued that for the purpose of social psychological discussion, the nature of personal identity has always concerned the “selves that are manifested in social encounters” (p.51) and are exemplified in how people act, which is a way of self-understanding, gathered through the reactions of others from social talk. The construction of selves as a product of discourse is an approach proposed by Harré (1991) and Harré and van Langenhove (1999) and founded on the notion that a ‘self’ is constituted and reconstituted as people interact and move within different socially arranged contexts (Linehan & McCarthy, 2000). Building on Wittgenstein’s philosophy of language games, Harré accepted that words are understood; however, meaning can only be interpreted by the ways in which the words are positioned in the discourse between the agents during social acts.

Positioning, [...] is the discursive process whereby people are located in conversations as observable and subjectively coherent participants in jointly produced story lines.

(Harré & van Langenhove, 1999, p.37).
2.11 A lifespan model of development — a way of seeing diagnosis as an unexpected event

The diagnosis of any chronic unexpected condition in an infant or young child can be a shock and disappointment for any parent. The impact of deafness on a hearing family is typically an unexpected event. Looking at events from a developmental lifespan view is a way of providing a context for the unexpected event (Sugarman, 1986). Baltes (1980) proposed a lifespan model of development as a linear and sequential orientation to understanding the flow of life events. A temporal approach tracks individual activity in relation to life experiences which are couched in personal and cultural history and extraordinary events. Individual variations arise mediated by three sets of influences (Sugarman, 1995). First, normative age-graded influences are those determinants that occur at similar times to all individuals at similar ages. They relate to physical and cognitive changes that take place within the normal biological and chronological maturation processes of the human organism. Second, normative history-graded influences are the significant events that occur at one point in time for a group, at any age, in similar ways. As a result of different events, a person’s individual development, their skills and talents influence their personal outcomes, for example, during wars, or serious health epidemics. Third, non-normative life influences are those that do not occur at any particular age or in historically related ways but are significant life events for people and have impact on the developing person.

It follows then, that events can be classified and occur in a background of pre-understanding gained from individual previous experience (Carr, 1986; Crossley, 2000a; Gadamer, 1976b). A Gadamerian view of experience, asserts that interpretation and reflection take place in a context referenced in shared understandings. For Gadamer, interpretation is always “on the way” as an evolving process from a human point of view; a person is always seeking a meaningful interpretation according to previous personal perspective. Any person’s interpretation of the meaning of a sequence of events depends on how each relationship is interpreted from a series of connections (Polkinghorne, 1988). Sarbin (1986) argued that connecting the actions of human encounters is the way people organise themselves:
A story is a symbolised account of actions of human beings that has a temporal dimension. The story has a beginning, middle and an ending...The story is helped together by recognisable patterns of events called plots. Central to the plot structure are human predicaments and attempted resolutions (p.3).

When people speak and as conversations unfold, different views of how people think about themselves are considered within different storylines as each become available. Human action is how we become aware of ourselves, engage with the other’s perspectives, the consequences of which are to define our personal characteristics, coping mechanisms and how we behave in certain situations (Crossley, 1996). However, it is not only about what people do but also about what they can do (Harré, 1991).

2.12 **Telling stories and adjustment to unexpected events**

Story telling about human experience is a way that people make sense of their lives and “acts of telling are relationships ” which confirm the human connection with events (Frank, 2000, p.354). Gadamer (1976a) asserted that the real event is when a person moves away from a fixed idea through a process of reflexivity and interpretation to reach an understanding that “goes continually beyond what can be brought to the understanding of the other person’s words by methodological effort and critical self control” (p.xxii).

Much of the available literature concerning experiences of sudden impairment or illness relates to adults. Such an unexpected event is variously described as “biographical disruption” or “narrative wreckage” (Bury, 1982). Kleinman (1988) described the impact of illness as an “ontological assault”. Crossley (2000b) argued that the “underlying existential assumptions that people hold about themselves and their world are thrown into disarray” (p.539). Some resonance can be considered here with the literature that highlights the stories of parents’ reactions to the unexpected diagnoses of illness or permanent conditions in their children. Increasingly, a phenomenological approach has been employed to illuminate the experiences of parents of diagnosis of disease or permanent conditions in their children by way of their personal accounts.
Haines (2005) conducted a phenomenological study to describe the experiences of parents whose children had suffered and survived meningitis. According to the parents’ accounts, the findings revealed that, apart from the emotional turmoil of the event during which time a parent’s constant fear was that their child might die, the early stages of the onset of the disease were marked by professional dismissal of their concerns. Reassurance for some parents about the lack of disease encouraged parents to take their children home. When a child’s condition deteriorated, usually during the night, parents were reluctant to seek medical help as a result of the negative experience of the previous consultation. When a diagnosis was eventually made and disease was far more advanced the parents were left feeling angry and frustrated. The researchers found for the parents in this study that “intuition and knowledge of their child is paramount to them knowing that their child was unwell” (p.86).

Parents’ experiences of adapting to their child’s epilepsy were explored in a phenomenological study conducted by Mu (2008). Results showed that parents were deeply shocked at first and their inherent belief systems significantly affected how they coped with the news. Initially these parents’ reactions were of a deep sense of loss, pertaining to the healthy child they thought they had. Other emotions such as anger, despair and guilt also emerged as themes linked to their negative perception of epilepsy and the cultural social stigma attached to this condition. Furthermore, the parents became socially isolated. Mu, defined the degree of parents’ adaptation to epilepsy according to how well they were able to revise their perceptions of the disease and redefine their views of parenting. Overall, what emerged from this study was a theme of transition and this finding contributed to health care workers’ reviews of their own practice.

Fitzpatrick et al. (2007) conducted an interpretative study designed to gain insight into the perceptions of parents of the diagnosis of childhood hearing loss. Parents self selection and purposive samples of parents provided two groups: one group whose children were identified through systematic screening and the other group with traditional detection experiences. Themes derived from the parents’ accounts revealed that the impact of the diagnosis was the same for all parents irrespective of whether it was diagnosed early as a result of a newborn hearing screen or later by traditional methods. The parents’ perspective
was that newborn hearing screening was preferable to traditional methods of diagnosis, as the stages in the confirmation process appeared to be clearer for parents who experienced systematic screening than for those exposed to traditional methods. What also emerged, however, was that the stated benefits of early detection and consequences of late diagnosis extended beyond speech, language and communication outcomes. Parents with children diagnosed after the first year of life (i.e. late) mourned the “fact that the child did not have full access to her environment in the early period of life” (p.105) even though, in some cases, the children had “caught up” in language development despite their late start. These parents were the greatest advocates for earlier detection. An interesting finding that emerged from both cohorts of parents was, on the one hand, a wish to retain universal newborn hearing screening and on the other, they felt no urgency to have their child diagnosed according to the age target set by most newborn hearing screening programmes. In conclusion, the researchers argued that the design of the study encouraged parents’ descriptions which served to highlight many contextual factors emanating from the larger health care system in the overall “health and wellbeing of children with hearing loss and their families” (p.106).

A study conducted by Davies, Davis and Sibert (2003) sought to identify how the lived experiences of parents were affected both positively and negatively by sensitive and insensitive clinical practices of paediatricians at the diagnosis of a permanent condition. Fourteen couples took part in the study. An important finding revealed parents needed to have their concerns validated and sensitive paediatricians, who were in the majority, were the ones who were able to enter the “life world” of the parents and understand their perspectives. Four parents’ experiences were of insensitive dismissal of their concerns, which resulted in late diagnosis. Insensitive practice was characterised as a “technocratic approach to care” (p.81), an inability or unwillingness to understand parents’ perspectives or enter their life world. In contrast, sensitive practitioner skill was demonstrated by the extent to which he or she successfully combined technical information with an understanding of parents’ needs, which the authors referred to as a “double obligation” (p78).
The literature draws attention to parents’ stories of a raising concern and their perceptions of something being wrong with their child. These studies have shown that parents’ experiences of the medical encounter, in this context, can be about a professional dismissal of concern (Becker, 1976; Davies, Davis & Sibert, 2003; Haines, 2005; Thompson & Thomson, 1991). Whilst Davies, Davis and Sibert found that the lack of acknowledgement of a concern may be accounted for by a lack of empathy or unwillingness on the part of the professional to engage with the parents’ perspectives, according to Becker it could also be that parents are inappropriately reassured. Donovan and Blake (2000) found that reassurance was an important and accepted part of a clinical consultation. Yet the effect of reassurance has typically attracted little interest from researchers because of a common assumption that patients are automatically “reassured by clear and confident statement about the diagnosis or the failure to find disease” (p.541). These researchers found that reassurance was not always successful because of the differences in points of view, about the nature of the problem, which exists between the physician and the patient. That these authors noted a “key to successful reassurance seemed to be the doctor’s ability to acknowledge patients’ perspectives of their difficulties” (p.541), resonates with the findings of Davies, Davis and Sibert to suggest that the quality of the reassurance may also be a factor.

Bruce and Schultz (2002) argued that when parents were exposed to a “litany” of negative medical facts about their child’s condition, they began to fear professional knowledge, which resulted in them avoiding professional contact. These authors interpreted parents’ stories in ways that revealed images of expertism that disconnected the professionals from the impact on the parents of the ways information was delivered. They found that professionals over-estimated what a parent understood and for some parents the intensity of the information was what was unbearable.

The literature reviewed in this section highlights the degree to which professionals’ and parents’ views of an event or topic are sometimes discordant. Taking into account the particular insights afforded by phenomenology and a hermeneutic approach to human understanding espoused by Gadamer (1976a), what emerges from these studies is the importance of how we understand one
another. van Manen (1990) argued that the process of reflecting on “lived experiences” assigns hermeneutic significance to them. This includes both the “trivial” and the “inconsequential” (p.37). The researcher accepts this view of human experience as one lived in relation to others and the nature of this relationship opens up the possibility of understanding the source for human action [agency] (Thayer-Bacon, 2003).

2.13 Phenomenology

The phenomenon of a medical diagnosis is a human experience embedded within a context of expected or unexpected life events in an ecology of social influences and relationships. The central question for this study is ontological. In the context of everyday lives what is it like for a hearing mother to discover that her baby has a permanent hearing loss and to receive this news? For hearing mothers, deafness is a condition that typically affects her child unexpectedly and few studies have sought to explore the steps and stages involved in diagnosis from a mother’s perspective (Russ et al., 2004).

Heidegger (1962) discussed the dynamic relationship between the ‘self’ and experience through a notion of a lifeworld. Heidegger established interpretation as a method of meaning making, of ‘Being’ (presence in the world) and what it means to ‘be’. He introduced the concept of ‘Dasein’, (the way of being-in-the-world) which refers to how human beings involve themselves in the world and cannot abstract themselves from it (Bleicher, 1980; van Manen, 1990; Wojnar & Swanson, 2007). Context is a central tenet of interpretative phenomenology (Geanellos, 1998), which views human beings as automatically ‘in the world’ and is fundamental to Heidegger’s thesis (Dreyfus, 1991). Our presence or being-in-the-world constitutes the basis for happening which opens our theorising related to both temporal and contextual space that Heidegger called a “forestructure” of understanding. Heidegger argued that each person perceives the same phenomenon in a different way as we each bring our own lived experience, specific understanding and personal history. Accepting this way of being-in-the-world involves a recognition that “researchers cannot help but bring their own involvement and fore-understandings into the research” (Findlay, 2002). Accordingly, the research process is a circular activity moving between the researcher’s pre-understandings and the research process.
This research review foregrounds the complexity of the domain of early identification of hearing loss in newborn babies and young children and a growing unease that centres on two central categories: professional language in relation to the diagnosis of profound permanent deafness in children and early management and the agency of mothers. As new technology has replaced older methods and practice in the curriculum of diagnosis, the issue of unquestioning acceptance of associated conventional practices and language use has demanded that professionals generate new ideas to keep institutional practices and language abreast of the times.

Purpose, goals and objectives in the frame of congenital hearing loss diagnosis are to do with available technologies, expected outcomes, plans for tomorrow and attempts to specify future behaviour of deaf children (Tomblin & Hebbeler, 2007). Inherent in these terms is the notion of value, and the pseudo-conflict between tradition and evolution and reconstruction. The process of achieving these objectives and the purpose of diagnosis involves inspection of the past (or the present as the already-past). Basically, the determination of such objectives is the search for the ridge between a mother’s past and her future with her child. These categories are concerned with treatment's existence "in time" and refer to concerns for continuity which gives social forms like families and institutions some kind of stability, yet vitality, as they emerge from yesterday into tomorrow in the process of diagnosis. Unfortunately, professionals’ easy acceptance of the function of or the requisite for technical purpose, goal or objectives has replaced an essential need for a basic temporal awareness or their historicity – of being and time.

As with the catalogues of purpose and objectives, learning also points to the temporality of professional and mother/deaf child. Learning has been associated with a change in behaviour of an organism. An observer, concerned with the learning of certain specified aspects of behaviour in any given time, seeks to identify a change in status. If change is detected and assumed to be related to interaction with the environment, then it can be said that learning has occurred or been prevented in this case. It is important to emphasise that ‘learning’ is a postulated concept. In the ‘learning’ category learning points to those aspects of a person's existence concerned with change and continuity, change and
permanence, or succession and duration. That is, this postulated category points to the fact that we are temporary beings, whose existence is not given by our occupation of space, but by our participation in an emerging universe, the meaning of which is shown in by the relationship between duration and succession.

The real question addressed in this research then, raised by recent literature and the authority of my professional experience, stem from inadequate explanations of human characteristics as they relate to new technologies of practice or from explanatory systems that force us to ask misleading questions. In framing this research, it seemed to me from the outset that the appropriate question concerned with improving professional practice in the area of the early diagnosis and management of congenital hearing loss, is not how to explain behavioural change or its absence in responding to the knowledge or beliefs of mothers, but how to explain the complexity of behaviour patterning. This required as a starting point a commitment to re-looking at the person of the hearing mother of a deaf child, their learning and later the limited forces of change available to us as professionals in this diagnostic period. A professional’s understanding is tied to the meaning of the mother's time, which necessitates their entering the mother's biography. The problems of change and continuity, both conditioned and unconditioned, or of fixation and creativity are essentially problems of our own temporality. We are not fixed beings. Our existence is not simply explained by being in a given place defined by a child’s sudden diagnosis of deafness, but is a present, determined both by a past and a future, offering possibilities for new ways of being in the anticipated future. In the exploration of this complexity, or perhaps the mystery of my own professional and person being in deaf education, time is not so much the scientific explanatory arrow but an existence to be described in this research. Although Heidegger's development of Dasein's temporality has been very fruitful in the conception and design of this study I do not intend or presume to present or interpret his phenomenological ontology except to say, I attempted to illustrate his principle that "Being-alongside...becomes possible in making present"  (Heidegger op cit. p.375)
Central to phenomenology are stories, which are the narrative constructions of people with real characteristics who are involved in day-to-day social activity. Communities and cultures contain beliefs, practices and meanings, which have been discursively produced and are inseparable from selfhood (Martin, 2005). Buber (1958) argued that conversations are the public activity of primary social groups. Knowing who we are is a core developmental task (Lewis, 1990) that continues throughout the lifespan with different levels of complexity and Bruner (1990) asserts that cultural histories shape personal biographies on which people draw to understand who they are. Likewise, Taylor (1989) considers a person to have a distinct personal history and capability to be called to moral account as a responsible actor. How to understand a particular moment of human participation in any social setting calls on social practice, agency and the significance that is afforded by such activity. This study depends on personal narratives and the mothers’ presentation of their perspectives through their conversations (interviews) with the author.

Diagnosis as a universal experience for mothers is not the issue for this thesis. From a phenomenological point of view, the mothers’ accounts represent their unique experiences according to each individual history and personal perspective (National Deaf Children's Society, 1990; Russ et al., 2004). The stories of hearing mothers and how they come to understand the experience of discovering their child’s hearing loss are part of their emerging life-world or umwelt (Harré, 1993), in a particular psycho-social space between family and primary health care. As a confirmation of hearing loss occurs in stages, professional practices are clustered around the social events of each of the stages through the intentional activity of health nurses, audiologists, ear nose and throat specialists and early intervention teachers or workers. How mothers stored their stories satisfied an innate human need to organise and make sense of their world (Buber, 1947; Sarbin 1986). Following Davies and Harré’s (1990) concept of positioning, this study focuses on the mothers’ accounts of their conversations with professionals, from which the mothers were able to map and understand their journeys and became committed to their actions.
Chapter Three: Methods

This phenomenological study investigates the assumptions involved in the everyday processes of confirmation and diagnosis of profound congenital hearing loss in young children. The study presents specifically the experiences of hearing mothers, derived from their stories (Strauss & Corbin, 1990) of systems for hearing screening, hearing testing and intervention in the UK and Australia. This study asks the question: how do hearing mothers experience or understand the diagnosis of deafness as an unexpected event? This inquiry refers to the use of qualitative approaches where narrative is central to human action (Polkinghorne, 1995). Polkinghorne describes two types of narrative inquiry; first a “paradigmatic analysis of narratives” and second “narrative analysis” (p.12), and is based on Bruner’s (1986) explanation of two ways of thinking. In the first view, the transcription data is analysed using paradigmatic analytical procedures to produce categories derived from common elements across the whole data set, whilst the second view proposes that data consists of actions, events and happenings and analysis involves their synthesis and configuration to produce stories as a research outcome. This current study employed the narrative approach to analysis because of a research interest in the nature of the relationships that mothers had in their encounters with professionals.

A dilemma for qualitative research exists with respect to rigour and validity. Mays and Pope (1995) state that in principle there are two goals that a qualitative researcher should seek to achieve with respect to rigour:

To create an account of method and data which can stand independently so that another trained researcher could analyse the same data in the same way and come to essentially the same conclusion; and to produce a plausible and coherent explanation of the phenomenon under scrutiny (p.109)

Lincoln and Guba (1985) suggest labels of trustworthiness and authenticity reflect validity procedures in qualitative research approaches and represent credibility and fairness. They are distinct from validity measures used in quantitative studies. Young et al., (2003) draw attention to how methodologies
are influenced by the object of study. For this current research mothers’ understanding of their experience of the early hearing loss detection process was sought through open-ended narrative interviews. The research interview is a widely used tool in qualitative research as a way of gaining a deeper understanding of a particular phenomenon from an insider perspective, to confirm our knowledge about our worlds. This type of interview reflected the author’s interest in relationships and the co-construction of meaning through conversation (Reissman, 1993; Van Manen, 1990). An ethogenic approach (Harré, 1983) is concerned with the talk that accompanies action. This view of a research conversation is a way of making sense of the social context of sequences of action which concentrate on developing a meaning system. Data produced through the creation of meanings are influenced by the nature of the relationship between the researcher and the participant (Popay et al., 1998).

Hall and Callery (2001) recognised the importance of the relationship between the researcher and the participant within which data are constructed. They proposed that reflexivity and relationality provide criteria for rigour to highlight not only how the data was created, but foreground the social processes that have influenced the generation of data. In this current study, a reflexive methodology enabled mothers to choose what was important to them in the hearing loss detection process to construct their experiences. Schwandt (1997) defines reflexivity as the process of critical self-reflection in relation to biases, theoretical standpoints and preferences. Potter (1996) argues that reflexivity is an essential part of people’s everyday actions produced in a localised context; it is about ‘doing’ something. Rather than advocate for a series of controls, as with a grounded theory approach, Strauss and Corbin (1998) acknowledge the intersubjective construction of the data and reject a mechanical approach to data collection implicit in other qualitative approaches. Barbour (2001) argues that qualitative research cannot be reduced to a list of technical procedures that guide sampling, data collection and analysis. Methods such as purposive sampling, triangulation, cross-checking (respondent validation) cannot in themselves confer rigour unless they are “embedded in a broad understanding of qualitative research design and data analysis” (p.1117). Similarly, Buchanan (1992) argues that the quality of qualitative research lies in the power of its
language to portray the world in “which we discover something about ourselves and our common humanity” (p.119).

Studies such as this often rely on participants’ memory and recall of events; indeed it may be possibly the only option for collecting information. In acknowledging some of the shortcomings of retrospective data, e.g. the extent to which events are forgotten, the personal narrative of each mother is accepted as her present self and there is an intimate interplay between one’s self and one’s personal history (Thayer-Bacon, 2003); the self of the mother is crucial to the development of her autobiographical memory. When she refers to the past, it is to a drama in which she is the leading player and her acts, which are active constructions, are embedded in a “social weave of dialogues” (Wang & Brockmeier, 2002, p.42) and cultural practice (Martin, 2005).

This current study was in two parts and employed mixed methods. The data were collected in the UK in 1999 and later in Australia in 2008 before the widespread implementation of Newborn Hearing Screening Programmes (NHSP) in birth hospitals. In this chapter, ethics approval, procedures involving the questionnaires, the design and distribution are described for Part One of the study. Then the sampling and selection procedures and the methods used for the data collection and analysis for Parts Two of the study are described.

3.1 Ethics approval

Ethical approval was sought from several sources. In the UK, The North Devon and Exeter Health Care Trust granted ethical approval in addition to that given by The University of Exeter Ethics Committee. In Australia, approval was granted by The University of Melbourne Human Research Ethics Committee (072196.1). Approval to conduct the research in their requisite Australian states was also granted by the South Australian Department of Education and Children’s Services and the Education Departments of Tasmania, Western Australia, Queensland and Victoria. There was no anticipated risk to the participants who were advised that the data would be written up as a collection of stories about their experiences of their child’s diagnosis of hearing loss as an unexpected event. Two names and addresses were placed strategically on the
tear-off sheet on the questionnaire form advising of a person to assist with debriefing should any participant require it.

3.2 Questionnaires procedures

The purpose of the questionnaire was to identify hearing parents with children with a severe or greater loss of hearing, younger than seven years of age and wearing a cochlear implant, who wished to participate in the study. There were two reasons for selecting this group of families. First, it was assumed that a severe or greater hearing loss would be noticeable to a mother in the first six months of life. Second, it was possible to explore the impact of significant permanent deafness on hearing families. Further, all the influences of professional support, including the part played by cochlear implant information and decision making, could be examined during the early stages of parents’ engagement with specialist habitation and intervention services.

3.2.1 Questionnaire design

The questionnaire was designed in two parts. The first part sought demographic information about the respondent, the family and the deaf child for the purpose of location, contact and grouping a sample of pre-school deaf children only. The second part sought information about a family’s experience suspicion and confirmation of hearing loss, the professionals they met and the events that unfolded before they made a decision about a cochlear implant. The questions relating to the process followed a continuum that represented a typical sequence of events for families in the detection process, early auditory management and engagement with services which are summarised as follows: suspicion and screening, hearing testing and confirmation; amplification and hearing device fitting; information gathering and decision making. Minor adjustments were made to the questions in the Australian questionnaire to include the experience of newborn hearing screening and accommodate the differences in naming of professional roles (e.g. speech pathologist as opposed to speech therapist) and medical/audiology department titles (e.g. Base Hospital as opposed to Community Medical Centre).

A variety of response types were used to elicit the information. For example, questions relating to time periods between events or specific ages when events
occurred were either specific times (e.g. 1 week) or blocks of time (e.g. 1-3 months). Some questions required respondents to choose between true or false statements. For example, concerning hearing aids, ‘He/she likes to wear them’ or ‘Hearing aids made little difference’. There were also opportunities for respondents to write personal qualitative replies to some questions. An example of this was, ‘when you were sure your child had a hearing loss what did you do?’ For some questions multiple responses could be made. This allowed for a comprehensive picture to emerge that could characterise each family’s experience. For example, ‘Can you remember who first spoke to you about your child’s hearing loss?’ or ‘How did you hear about a service or programme for hearing impaired babies or pre-school children in your region?’ offered a list of professional roles for respondents to choose from and/or space to add their own.

3.2.2 Questionnaire packs
In the UK, the questionnaire pack sent to parents included a letter of invitation to participate and a questionnaire. In Australia, the questionnaire pack also included a plain language statement and a prepaid reply envelope. Each prospective participant self selected, by signing the questionnaire form after completion. Broadly speaking, families could respond to the questionnaire in one of three ways. First, they could self-select by completing the questionnaire, signing and returning it to the researcher with their first names and telephone contact details. Second, they could complete and return the questionnaire to the researcher unsigned, which allowed their information to be used for analysis in Part one of the study, without further involvement in Part Two. Finally, respondents could do nothing. In either of the first two options, respondent confidentiality was assured.

3.2.3 Questionnaire distribution
To recruit participants in the UK, six hospitals were contacted where cochlear implant surgery was performed. The researcher outlined the project to programme leaders or managers. Only one hospital in London indicated their willingness to distribute the questionnaire to parents. As a result of a discussion with this programme leader, a national organisation for parents with children with cochlear implants was identified. This organisation operated in two
specific regions, the north and the south of the UK and the researcher contacted this organisation and the committees agreed to send out the questionnaire packs to all families named on their lists. This yielded a total of 39 respondent families in the UK with children wearing cochlear implants at the start of the data collection.

In Australia, a second cohort of participants was recruited in a similar way although the distribution of questionnaire packs was effected through specialist early intervention programmes. The questionnaire form was similar to the one used in the UK, except for the revisions previously described, to include extra questions that related to newborn hearing screening. This was necessary because newborn hearing screening programmes were in place in selected birth hospitals in Australia at the time of the research. Both private and state funded early intervention agencies from every state or territory of Australia, except for the Northern Territory, were invited to participate in the recruitment process. This involved an initial telephone contact with directors or team leaders of programmes. In most cases, team leaders requested that a questionnaire pack was sent out initially for review by staff, boards of management and/or managing authorities. In contrast to the UK recruitment process, where only families with children with cochlear implants were approached, the directors of Australian services distributed the packs to all families enrolled in their programmes. As a consequence, 142 respondents were located with children with all ranges of hearing loss. This represented 150 deaf and hearing-impaired children because some families had more than one deaf child. Of these children, 96 wore hearing aids, 53 children wore cochlear implants and one child with auditory neuropathy was not wearing any device.

All the Australian families with children wearing hearing aids that could be contacted were thanked for their participation. They were advised that the focus of the next investigation, Part Two of the study, was pre-school children who were cochlear implant users. These children and the child with auditory neuropathy were excluded from the study (n=97). This yielded a total of 53 families in Australia with children wearing cochlear implants before the age of seven years. Of the 53 children in the cochlear implant group, 22 had been diagnosed as a result of newborn hearing screening and 31 were diagnosed by
other methods. All the questionnaire respondents, UK (n=39) and Australia (n=53), were allocated a coded number and data were entered on to a database without any other identifying features.

3.3 Questionnaire respondents

All respondents in both the UK and Australian were mothers. Figure 3.1 shows that boys and girls were equally represented. In the UK cohort there were 19 boys and 20 girls and in the Australian cohort there were 27 boys and 26 girls. The ages of the mothers at the time of research are shown in Figure 3.2.

![Distribution of boys and girls in the total UK and Australian cohorts.](#)

*Figure 3.1* Distribution of boys and girls in the total UK and Australian cohorts.
Figure 3.2 Ages of the mothers at the time of research

3.3.1 UK demographic

Figure 3.3 shows the range of the ages of the children, at the time of the research, to be from 24 months to older than 5 years. Figure 3.4 shows the position of the deaf children in the family and Figure 3.5 shows the sizes of the families in the UK.
3.3.2 Australian demographic

Figure 3.6 shows the range of ages of the children, at the time of the research, to be from younger than 12 months to five years or more.
Figure 3.6  Ages of deaf children at the time of research in Australia
Figure 3.7 shows the positions of the children in the family. Twenty-one deaf children were first and second born, 8 were third born, 2 were fourth born and one was fifth born. The sizes of the Australian families are shown in Figure 3.8

Figure 3.7  Position of deaf children in Australian families
3.3.3 Grouping of questionnaire respondents

The questionnaire generated two groups of respondents irrespective of the country of origin. First, respondents with babies not screened at birth and identified by other methods, coded non-NHSP (non-Newborn Hearing Screening Programme), and second, respondents with babies screened for hearing loss at birth, coded NHSP (Newborn Hearing Screening Programme). All the 39 children in the UK were in the non-NHSP group and of the 53 Australian children, 31 were in the non-NHSP group and 22 in the NHSP group. Given the criteria for parents to participate in the research, children needed to have received a cochlear implant, the differences in the ages of the children between the UK and Australian samples represents the changes to cochlear implantation protocols since the start and the end of the data collection.

3.4 Sample sizes and selection for interviews (Study Part Two).

In the UK, of 39 respondents, 37 signed their questionnaire forms to express willingness for further involvement with the study and in Australia, of 53 respondents, 42 similarly gave their consent to be contacted. All these mothers were contacted by telephone and thanked for their participation. They were advised that information from the questionnaire would be included in quantitative data analysis in Part One of the study. Each respondent was then asked if they consented to further involvement in Part Two of the study, which would involve two interviews and all agreed. However, preliminary telephone conversations confirmed the questionnaire data that some deaf children were outside the criteria for Part Two of the study, which was, that at the time of the
study all the children needed to be younger than seven years of age and have a cochlear implant. Figures 3.9 and 3.10 show the reasons for the exclusion of families from Part Two of the study.

![Figure 3.9 Selection of sample for Study Part Two (UK).](image)

**Figure 3.9 Selection of sample for Study Part Two (UK).**

In the UK, five mothers were excluded from the study because of their children’s ages. Also excluded from the sample were four children with meningitis, three families living outside the area or at a reasonable distance from the university and two mothers who refused consent for interview. This left an opportunistic sample of six mothers.

In Australia, all the children met the age and device-wearing criteria because respondents were recruited from early intervention programmes. Because the interviews were undertaken on the telephone, distance was not a reason for exclusion of Australian respondents as in the UK cohort. However, to avoid any variable factors that could affect the timing of diagnosis, such as neonatal ill health, additional family commitments caused by multiple births, hereditary deafness, intrauterine infection or where hearing loss was not the major presenting issue, 35 mothers were eliminated from the study. Their children were in the following categories: prematurity/low birth weight/multiple births/craniofacial deformity accounted for five children, four children were deafened
by meningitis, two children were exposed to cytomegalovirus (CMV) and 13 children had deaf siblings. This left a purposive sample of 18 mothers.

![Figure 3.10 Selection of sample for study Part Two (Australia).](image)

**Interview procedures**

Respondents had specified on their forms suitable days and/or times for an initial telephone call to make appointment times for interviews. When telephone contact was made, after the greetings, mothers were informed of two things: first, the purpose of the study and the research focus being on the respondents’ own accounts of the discovery of their child’s hearing loss and their decision to have a cochlear implant, and second, that two interviews would be required. The interviews were conducted in the homes of the UK respondents and audio taped and by telephone with the Australian respondents because of the distances involved. The Australian mothers also gave permission for (1) the researcher to take notes over the phone during the first interview and (2) for a digital tape recorder to be used to record the second interview.

The interviews were open-ended and conversational and they were undertaken in the same way in both countries irrespective of how they were conducted, either face to face or on the telephone. All respondents were asked at the end of
the session if the interview had caused them any concern. No respondent said that this had been the case. All participants were informed of the measures that would be taken to preserve their anonymity with real names being replaced with codes in the transcriptions. No locating information was recorded and references to specific programmes, hospitals or audiology departments were removed and replaced with generic terms e.g. ‘audiology clinic’ or ‘education department’.

**Interview 1:** Each participant’s questionnaire data were scrutinised and used to inform and guide when necessary the conversations from the researcher’s perspective. For example, using the questionnaire data, a preliminary question may have been, “I see you noticed very early that your baby did not respond to your voice?” or “I notice that it was your own mother who was concerned that your baby had a problem”.

**Interview 2:** At the start, the researcher reviewed the main points of the first interview from a short résumé taken from the transcription of the audiotape (UK) or notes (Australia) for the purpose of authenticity and confirmation (Creswell, 1998; Hammersley, 2000). Respondents were asked if the résumé accurately reflected their understanding of their own stories and they were invited to make revisions. No revisions were made. Respondents told their stories again in an unstructured way, encouraged, if necessary, by questions posed by the researcher arising from the reading of the texts of their earlier stories. Occasionally, prompts were necessary to maintain continuity especially when more difficult or sensitive issues arose. Alternatively, a reflexive technique for elaboration was used such as “You said you felt angry that no-one was doing anything. Can you tell me more about this feeling at that point in time?” or “So at the end of the day when they said there was nothing wrong with him, how did that make you feel?”

The audiotapes were transcribed verbatim. Where interview data were gathered face-to-face, as in the UK, nonverbal communication was noted and included in the transcriptions e.g. pauses to indicate thoughtfulness or uncertainty. Only one mother in the UK told her story with her husband as a couple and any co-referral was noted on the transcript. Similarly, in the Australian telephone interviews, voice tone, changes to the speed of delivery and pauses were
checked out with a respondent, by saying for example, “you hesitate here, you seem sad?” or “you sound really happy now, why was this?”

Questions directed towards the researcher with respect to her own knowledge or experience, for example, “Well you would know what it’s like?” or “I expect you would have done the same, wouldn’t you?” were respectfully re-directed in the same way for all participants saying, “This is your story and everyone’s different. I’m interested in how it was for you”.

3.6 Analysis of quantitative and qualitative data

Two principal data sets were gathered providing three levels of data. First, quantitative data gathered from the questionnaire responses provided a timeline for each case and foundational information about the flow of the process of hearing loss confirmation for the families. Second, qualitative data were obtained from the combination of notes, face to face or telephone conversations. A preliminary analysis of data generated from the questionnaires was performed to produce frequency counts using Microsoft Excel and cross tabulations using Statistical Package for Social Science (SPSS).

3.6.1 Interpretative approaches to qualitative data analysis according to Interpretative Phenomenological Analysis (IPA)

Notes from telephone calls and verbatim transcriptions from the first and second interviews were combined to produce a whole narrative text for each participant. According to Wittgenstein (1968) reading of texts may occur on two levels, primary and secondary and he made a distinction between the two. A primary reading provides information whilst a secondary level of meaning is less easily dealt with and demands a degree of competence and an understanding of the context (van Manen, 1997). Patton (1980) argues that credibility is determined by the extent to which the data are saturated to establish good themes and how the analysis of the data evolves in to a persuasive argument. He describes this process as one where the research analyst returns to the data “over and over again to see if the constructs, categories, explanations and interpretations make sense” (p.339). A phenomenological interpretative approach was taken to examine the perspectives of the mothers revealed through their stories, specifically the
location and context of the unexpected within their everyday world. Polkinghorne (2005) argued that the accounts that people give of an event provide the evidence of the experience on which the findings are based. Excerpts from mothers’ accounts served to illustrate the findings and my biographical experience enabled me “to enter the relations of storytelling” (Frank, 2000, p.355).

According to Smith and Osborn (2003), phenomenological reflection requires two steps in thematic analysis: first for the purpose of illumination, and secondly for the determination of essential themes. Data analysis according to the hermeneutic tradition is a way of seeking meaning embedded through themes. Themes that emerged from mothers’ experiences as common or typical of their experiences of diagnosis are a way of getting to a notion within the phenomenon and they “give control and order” (van Manen, 1990, p.79) to the research writing. They are the “plotlines” (Polkinghorne, 1988) in the mothers’ accounts.

Interpretation, after Smith (2003), of the transcriptions required first, a preliminary reading of the mothers’ conversational interviews for the purpose of familiarisation with all the stories as a whole data set. The texts were treated as holistic data in the sense that passages were not selected specifically nor were themes generated from every line of text as illustrated in Appendix C.

Two margins drawn down each side of the texts, allowed for note taking either as interesting or significant details emerged on one the one hand or as the researcher’s personal reflection and thoughts on the other. According to Smith and Osborn (2003), the task of the researcher is then to make sense of the participant’s attempts to make sense of their world through a process of reflection, which call the authors call a double hermeneutic.

Using an idiopathic approach, a closer sustained and systematic reading of each individual text, the words and phrases the mothers used to tell their stories including these preliminary notes, captured personal meanings, e.g. “worried” or “not really worried” and the significance and timing of events, e.g. ”I wanted the hearing aid quickly” or “we just waited for that appointment”. Coding into primary and secondary themes emerged specifically from this procedure. The
quantitative data was used to provide the scaffold for the clinical flow to the
events of the detection process from which to gain a deeper insight into the
mothers’ accounts and how a diagnosis unfolded according to their perspective
of the timing of events.

A computer programme, SuperHyperqual for Macintosh (Padilla, 2004), was
used to record and store the themes for each participant. This was a useful
software tool for the purpose of collecting similar or dissimilar themes. This
programme uses a library-card system of marking and ‘tagging’ chunks of data,
which identifies ‘tagged’ data chunks either for further higher order analysis or
comparison across the whole or individual data sets. It was also possible to
identify chunks of data with different codes. The programme also allowed for
‘untagging’ and reduction of themes to allow for re-clustering clustering under
new or different codes. SuperHyperqual has the capacity to produce a list of
themes for each respondent (individual thematic analysis) or for the cohort as a
whole. Clusters of primary themes were then recorded and printed in colour on
a Microsoft Excel spreadsheet, illustrated in Appendices C, D, and E. In this
way, a condensed thematic representation of each respondent’s story was
produced and used to identify similarities and differences in the mothers’
accounts.
Chapter Four: Results

This chapter presents an analysis of the data derived from both the questionnaire and the interviews with mothers of profoundly deaf children. The questionnaire data were analysed and illustrated using frequency counts and distribution bar charts. The interview data were analysed according to IPA (Smith, 2003). The questionnaire data broadly acted as a linear representation of the significant events in hearing loss detection and confirmation. They provided reference points and a sense of procedure in which to contextualise the mothers’ experiences and are presented first. Where it is appropriate however, both quantitative and qualitative data are presented together. The primary themes that emerged from the interview data are illustrated with verbatim quotes from mothers, and occasionally, where themes have emerged from respondents’ qualitative statements in the questionnaire data, which could be clustered, these data are presented separately. For the purpose of clarity, until the point of diagnosis both the UK and Australian non-NHSP data are presented first and the Australian NHSP data are presented second.

4.1 Concern about a hearing problem, non-NHSP cohort

The quantitative data showed that mothers, in both the UK and Australian non-NHSP cohorts, were generally the first to suspect a hearing problem in their babies. In babies younger than six months of age, 12 mothers in the UK were concerned first about their babies’ hearing and 11 mothers in Australia. These results are shown in Figures 4.1 and 4.2.
Figure 4.1  **UK: Person most likely to suspect a hearing problem in babies younger than 6 months**

Figure 4.2  **Australia: Person most likely to suspect a hearing problem in babies younger than 6 months**

People other than mothers in both countries raised of concern in similar frequency. In the UK, these were grandparents (n=2) and child health nurses.
and ‘other’ medical practitioners together (n=2). In Australia these were one set of grandparents and child health nurses (n=2) and other medical (n=3).

Each questionnaire respondent was asked to identify two points in time, which were (1) when a concern about hearing was raised and (2) when a formal diagnosis confirmed permanent deafness. This then allowed ‘delay’ to be measured between the two points. The choices were offered in blocks of time: 0-3 months, 4-6 months, and then in six monthly time periods after that until 36 months. An average time was calculated from the time a concern was raised until a diagnosis was made and was represented by a coloured bar. The bottom of the coloured bar signifies the time a concern was raised whilst the top of the bar shows the time a diagnosis was made.

Analysis of these data revealed two noticeable patterns of delay between the two events. A short coloured bar indicated a delay less than three months and a long coloured bar a delay longer than three months. Table 4.1 shows how the respondents were clustered according to short or long delays and their country of origin.

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Short delay</th>
<th>Long delay</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK non-NHSP (n=39)</td>
<td>n=17</td>
<td>n=22</td>
</tr>
<tr>
<td>Australia non-NHSP (n=31)</td>
<td>n=15</td>
<td>n=16</td>
</tr>
</tbody>
</table>

4.2 Time between raising a concern and confirmation of hearing loss (non-NHSP)

The times between raising a concern and receiving a confirmation of a hearing loss are illustrated in Figures 4.3 and 4.4.
Figure 4.3  The time between raising a concern and receiving confirmation of a hearing loss for mothers in the UK (non-NHS).
Figure 4.4  The time between raising a concern and receiving confirmation of a hearing loss for Australian mothers (non-NHSP)
4.2.1 Results from the UK non-NHSP (n=39)

In the UK, 43.6% of mothers recorded a short delay and 56.4% of mothers, a long delay.

4.2.1.1 UK Short—delay pattern (n=17)

For 11 children (cases 1; 6; 11; 14; 18; 20; 21; 25; 28; 35; 37), concern started at nine months, and diagnosis occurred within four weeks. A Health Visitor Distraction Test (HVDT) routinely took place in the UK between the ages of seven and nine months, and this short delay pattern here suggests that the HVDT possibly identified a problem to provide a timely result for these respondents. For four respondents (cases 8; 13; 29; 36) a short delay pattern was also recorded for children younger than six months of age. In two of these cases, (8 and 36), respondents recorded that ‘other medical’ and a ‘child health nurse’ raised a concern whilst in the remaining cases, (13 and 39), it was the mothers. For the remaining two respondents (cases 7 and 39), concern was raised late by mothers and diagnosis occurred without delay. As these children were already aged sixteen months when their mothers raised a concern, these results may possibly be accounted for by a deteriorating condition or an adventitious hearing loss.

4.2.1.2 UK—long delay pattern (n=22)

For nine babies, concern was raised before the age of six months. In seven of these cases (cases 2; 3, 5; 10; 16; 23; 38) a concern was raised by mothers and by the grandparents in the two other cases, (12 and 34). Except in three cases, (3; 12 and 23), confirmation of hearing loss took place on or around ten months of age possibly as a result of a concern in combination with a HVDT. The long delay pattern in these seven cases suggests that the respondents were concerned before the HVDT, yet it is not clear from these data how to account for the delay. It was possible that mothers waited until the babies were old enough to perform a hearing screen. Mothers of three babies (cases 22; 30; 33) suspected their child of having a hearing loss at one month of age and a diagnosis was made at four months. Three babies (3; 12 and 23) suspected by their mothers of a hearing problem before the age of six months and received a diagnosis after their babies were twelve months old. Seven babies (cases 4; 9; 17; 19; 24; 26; 31) showed a long delay pattern with suspicion starting at nine months and six
mothers recorded that a health visitor suspected a hearing problem. This possibly suggests that the baby failed the HDVT, which indicated a problem. However, in these cases, diagnosis did not occur until the children were aged sixteen months. Three babies (cases 15; 27; 32) were suspected of having a hearing loss at sixteen months and waited a further six months or more for a diagnosis.

4.2.2 Results from Australia non-NHSP (n=31)
In Australia, 48.3% of mothers recorded a short delay and 51.1% a long delay and these patterns. Findings revealed mixed patterns of delay between the times of raising a concern and the confirmation of a hearing loss.

4.2.2.1 Australia (non-NHSP) — Short delay pattern (n=15)
Of eight babies (cases 4; 6; 13; 15; 22; 23; 26; 27) suspected of having a hearing problem in the first month of life and diagnosed within four weeks, six babies were suspected by their mothers and two by ‘other medical’. Three babies, (cases 14; 20; 28), were suspected of a hearing problem before they were six months old. Of these, case 14 was suspected by a grandparent caregiver and diagnosed within 8 weeks whilst for the remaining two cases, one was suspected by the mother and the other by the child health nurse and diagnosed within four weeks. Short delay patterns were revealed also for two babies, (cases 2 and 9) aged 16 months, and it is possible that a deteriorating condition or an adventitious loss of hearing accounted their deafness. Concern was raised for two babies, (cases 17 and 31), at 10 months and a diagnosis was recorded within eight weeks and four weeks respectively.

4.2.2.2 Australia (non-NHSP) — Long delay patterns (n=16).
Three mothers suspected a hearing problem in their babies (cases 5; 8; 19) in the first month of life and recorded a delay in diagnosis of 22 months, 10 months and four months respectively. One mother who suspected a hearing problem in her baby at 5 months recorded a delay of five months before diagnosis. In seven cases, (1; 3; 7; 18; 21; 24; 29), the time of concern began at 10 months and seven babies were diagnosed at 16 months of age. Long delays between concern occurred in five other cases (10; 12; 16; 25; 30); each of these babies were
suspected of hearing loss after their first birthdays and diagnosed between their second and fourth birthdays.

4.2.3 Summary
In the UK, the age of 10 months emerged as noteworthy in 25 cases (64.4%). For 11 (28.2%) cases, where a concern was raised about hearing on or around the age of ten months, a diagnosis followed within a month, whilst for 7 cases (18)% a diagnosis was recorded at a later age of 16 months. In 7 cases, the age of 10 months was the age of diagnosis that followed four months or more of concern (delay). These data possibly suggest that a Health Visitor Distraction Test played a part in the detection of hearing loss for 64% of the total cohort of the UK families. Specifically, these results also show that 20% of families either suspected for four months or more before the age of 10 months and the delivery of the HVDT. The same percentage of mothers waited for six months or more after.

In Australia, the patterns of delay were more variable. Eight mothers (25%) recorded a concern and confirmation of hearing loss followed for their babies on or before the age of three months compared to the UK (7.6%). Unlike in the UK, the age of 10 months was relevant only for 11 (35.4%) of the Australian mothers and rarely resulted in a diagnosis, with only two mothers recording a diagnosis within a month of this age. Noteworthy here were the findings revealing that seven mothers (63%) received a diagnosis at 16 months of age, six months after a concern had been raised.

4.3 Mothers and their concern about hearing
The interview data revealed how mothers became concerned about hearing. They reported that, at various times during their babies’ early development, concern started as a feeling of unease about their baby’s behaviour, after which they began to suspect a hearing problem. The mothers described this feeling as either their baby’s generalised lack of response to sound, or failing to behave age appropriately as they had expected. Importantly, however, mothers also said that their babies were not always consistent in their responses or behaviour before the age of six months. The following quotations reflect two mothers’
intuitions about something not being right and highlight an understanding that, until this point, they had considered their babies were healthy.

“I just think it's one of those things that you know when your baby's born if there's something wrong with them or not. They come out and they're fine; they get ticked off and you get sent home from hospital.... you know they're fine. So yeah, it's that whole feeling that something can be underlying that you know nothing about. (A11)

…so a sense that something wasn't quite right with ‘baby’. Yes that things just weren't happening right....in the right order. (A10)

Four mothers in the UK talked about vague feelings of something not being right, whilst one mother reported a more definite sense that something was wrong. In Australia, three mothers believed something to be specifically wrong with their babies before the age of six months. Five Australian mothers noticed a difference in their baby’s behaviour later than six months but before the baby was twelve months old. Four mothers noticed differences after 12 months.

A systematic search of the interview data revealed three categorisations of baby behaviour. The first category was unusual or unexpected behaviour that occurred before the age of six months that could be defined as an ‘early concern’, e.g. a lack of startle reflex or fright. The second category was a ‘late concern’ that occurred at a time later than six months of age which related to a lack of head turn in response to a voice, babbling and delayed speech. Thirdly, mothers reported a ‘pivotal moment’ which occurred at any age when a baby’s response to sound could not be explained in any way other than the baby had not heard it. A pivotal moment often endorsed mothers’ earlier concern. Nine mothers in the total cohort of non-NHSP babies described a pivotal moment.

Table 4.2 presents a résumé of mothers’ concern, their experience as a mother and their babies’ behaviour according to the above criteria.
Mothers also justified how they became concerned according to their views of their own experience as a mother. They described themselves as being experienced or inexperienced according to the following criteria: 1) having raised other children; 2) being involved with a playgroup; (3) having another child with, or knowing about, conductive hearing loss or (4) being a nurse.

### 4.4 How concern shapes mothers’ action

Figures 4.4 and Figure 4.5 show the individual quantitative data for the mothers who were interviewed. The concerned mothers in these groups (UK n=5) (Australia n=11) did one of two things, they waited or they asked someone. Individual case data were placed together with the mothers’ accounts which

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**Table 4.2 Incidence of mothers’ concern, maternal experience and baby behaviour. In the UK and Australian non-NHSP cohorts.**

<table>
<thead>
<tr>
<th>Mother</th>
<th>Concern</th>
<th>Experienced</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK1</td>
<td>No</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>UK2</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour</td>
</tr>
<tr>
<td>UK3</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour; no speech/ ear nose and throat specialist supervision</td>
</tr>
<tr>
<td>UK4</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour</td>
</tr>
<tr>
<td>UK5</td>
<td>Yes</td>
<td>No</td>
<td>Behaviour</td>
</tr>
<tr>
<td>UK6</td>
<td>Yes</td>
<td>No</td>
<td>Behaviour</td>
</tr>
<tr>
<td>A1</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour; no speech</td>
</tr>
<tr>
<td>A2</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour</td>
</tr>
<tr>
<td>A3</td>
<td>Yes</td>
<td>No</td>
<td>At risk factor/child health nurse alerts mother</td>
</tr>
<tr>
<td>A4</td>
<td>No</td>
<td>Yes-also nurse</td>
<td>Ear nose and throat specialist supervision; conductive Hearing loss</td>
</tr>
<tr>
<td>A5</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour</td>
</tr>
<tr>
<td>A6</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour/ conductive H/loss</td>
</tr>
<tr>
<td>A7</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour</td>
</tr>
<tr>
<td>A8</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour; no speech/ ENT supervision</td>
</tr>
<tr>
<td>A9</td>
<td>Yes</td>
<td>Yes-also nurse</td>
<td>Ear nose and throat specialist supervision; sibling slow to talk; speech therapy</td>
</tr>
<tr>
<td>A10</td>
<td>Yes</td>
<td>Yes-also nurse</td>
<td>Behaviour</td>
</tr>
<tr>
<td>A11</td>
<td>Yes</td>
<td>No</td>
<td>Behaviour</td>
</tr>
<tr>
<td>A12</td>
<td>Yes</td>
<td>Yes</td>
<td>Behaviour; no speech</td>
</tr>
</tbody>
</table>
revealed how experience influenced their concern to justify seeking professional help or waiting.

4.4.1 UK mothers
Of five concerned mothers in this cohort three were experienced.

![Figure 4.5](image)

**Figure 4.5** Time taken from raising a concern to confirmation of hearing loss for mothers in the selected sample in the UK (n=6)

Mother UK5 was an inexperienced mother and alerted to the problem by her mother-in-law. She decided to wait until the time for the next formal developmental check.

> My mother-in-law who is blind...she helped us look after her while we were working in the shop...then she realised although she couldn’t see herself very good, ‘baby’ definitely have something wrong with her hearing, she wouldn’t like to upset us and she waited until she pretty sure and she say “OK you have to do something about your child” so when baby is eight months old she say she definitely have some problem with hearing. (UK5)

Mother UK6, also inexperienced, was unsure about the behaviour she observed in her newborn baby and she checked with her health visitor. She was reassured so she waited.
……but when it’s your first child you’re not quite sure, all babies are different. I said to my health visitor when she was just a couple of weeks old... “Do you know when the jets go over” because we get a lot of jets out here, “she doesn’t startle” and she clapped her hands and she didn’t do anything and she said, “All babies are different, don’t worry about it she’ll be fine.” So I often wonder whether I had this gut feeling that something wasn’t…you know….? (UK6)

Although this mother felt reassured at that time, a specific incident later was to be a pivotal moment that revived her previous early concern:

And my Dad was going in the loft and he dropped the ladders, and there was such a crash and (Baby) was just sort of sitting about and I remember her sitting on my mum’s knee, and she didn’t…and they knew then there was something not right. (UK6)

Two experienced mothers, (UK2 and UK4) were concerned early, because their babies failed to startle. Both mothers also recalled pivotal moments, which happened later and appeared to explain their behaviour as a hearing problem.

And then when you touched her, if she was asleep and you touched her, say if you banged the pram or something she would jump... she would jump awake, not come awake, she would...you know…jump? (UK4)

Then, for this mother, the pivotal moment happened during a family argument:

I remember her actually on the floor or mat or whatever, dozing and I had an argument with my father//and there were raised voices and I can remember thinking, ‘Well why didn’t she wake up?’....raised voices ...in the same room. They were yelling. Anyway, only when he’d gone...// we did think... there is [emphasis] something wrong here....must be deaf we thought....but ermmm...... it never really sunk in. (UK4)

Mother UK 2 told a similar story, except in reverse, in that the specific incident came first with a door slamming and her baby failing to react. The mother said that after that pivotal moment, she spent her time rattling and banging things next to her baby to try and provoke a reaction.
There was just something inside me that told me that there was something very wrong going on here and I actually picked him up and spent the next hour, sitting on the table and bashing things down on the table trying to get him to respond.  \textit{(UK2)}

After this moment, this mother went on to observe this lack of response consistently in other more general situations. Neither mother waited preferring instead to contact their health visitor.

\subsection{Australian mothers}

Of 11 concerned mothers in this cohort, eight were experienced.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure4.6.png}
\caption{Time taken from raising a concern to confirmation of hearing loss for mothers in the selected sample in Australia (n =12).}
\end{figure}

In the Australian cohort, of the three inexperienced mothers (A3, A10 and A11), two A10 and A11 had similar stories of waiting. Although Mother A10 was inexperienced as this baby was her first child, she also described herself as both an "older mum" and a nurse. She reported that these definitions played a part in her not raising a concern. Although she had noticed her baby’s generalised lack of response to sound, she waited until her baby passed his first birthday, in spite
of a pivotal moment when a glass bottle smashed and there was no response from her baby. Mother A11 also had observed her baby’s inconsistent responses to sound, then, she recalled a specific incident. Her baby, facing away from a group of people who were talking loudly and laughing, appeared shocked and frightened when she turned suddenly to see the crowd of people.

Mother A3 also waited, although her story was different. An alert child health nurse flagged a concern about hearing because of the time her baby spent in the Special Care Nursery. The mother said she was reluctant to agree with the nurse at first although she agreed to monitor her baby’s development herself. Being uncertain about the risk, she asked her obstetrician less than six weeks after the baby’s birth.

I had to go back to the doctor because I had had a bad time after the birth, and I had to have some stitches checked and I mentioned to my obstetrician, I said, ‘Listen this health nurse is on me about you know, that ‘baby’ isn’t responding to the bell,’ and he was just very dismissive, he just said, “Just don’t worry about it.” (A3)

Later, despite her doctor’s reassurance that there was no risk, the mother reported her baby’s lack of response followed by a specific incident. She agreed then with the nurse that there was a problem and organised a hearing test, which resulted in a diagnosis.

With regard to the experienced Australian mothers, six described how their babies’ early behaviours first alerted them to a problem, the consistency of which was enough to sustain their concern, although only one mother (A5) asked her child health nurse during a routine health clinic visit in the first three months. Four experienced mothers reported generalised early concerns similar to those previously described by mothers in the UK, before a specific incident occurred.

It was a 21st, so as you can imagine there was a lot of loud ‘duff duff’ music and everything like that and lots of people coming up and talking to her and she basically just didn't respond to virtually anything. (A6)

None of these four mothers did anything until after their babies were older than six months. However, one experienced Australian mother (A2) told a different
story of her early concern. The mother reported that it was difficult to get the child’s attention, then she noticed that the baby displayed an unusual behaviour; she seemed unable to focus on the mother’s face and she said that her baby “seemed to look through you and she had no eye contact”. This mother said that it was just as though she was looking into the distance all the time. The mother thought the baby had a visual impairment. When the baby’s vision was found to be normal, the mother remained convinced that something was wrong. Not long after, there was a pivotal moment that confirmed this mother’s fears. As she was vacuuming, her baby’s lack of response alerted her to the fact that the problem was with hearing and this probably explained the baby’s unusual behaviour.

Nine mothers told how their babies’ developmental milestones in speech and language caused concern. These mothers reported that their babies failed to babble, develop speech-like sounds, or start to talk. Of these mothers, three had previously noted their babies’ inconsistent responses to sound during the first six months. Only one mother in the UK was in this category because her baby was slow to talk. Two mothers in Australia noticed a different vocal quality in the babbling; one remarked that it was guttural whilst another called it “grunting”. Another mother reported loud screaming.

[she] used to make all these gabble vibro-tactile sounds but that was sort of it…So when it was time to start talking she didn’t start saying ‘dad dada dad dad’….‘mum mum mmmm’ she never said any of that. Screaming loud enough so she could either feel it or hear it. (A7)

Three Australian mothers. (A1, A4, and A9) reported that their baby’s failure to start to talk was their first concern and their experience as mothers supported this view.

…..I expected just some noises that were speech like. I didn't expect her to talk…….[pause] I expected maybe a couple just words or just well.....yeah.....a word. (A1)

Conversely, two Australian mothers said that their experiences with siblings being ‘slow to talk’ clouded their views and challenged their concerns.
…in my mind, part of me wasn’t concerned because our eldest child didn’t speak until he was 2, didn’t speak at all. He did babble a bit as a baby but didn’t speak until he was 2, he had very good language development like he understood everything that you were saying like that, so because (deaf baby) wasn’t speaking and babbling didn’t particularly worry me. (A4)

I wasn’t real worried like I said I’ve not been a person who has stressed out about milestones and as ‘sibling’ was a slow talker and he eventually got there// and like you just had a lot going on so no time to sit back just focussing on speech. (A9)

Just as some experienced mothers talked about accepting differences, other mothers seemed reluctant to compare children.

I was involved with playgroups with my older son and with her and I wasn’t seeing other babies behave that way you know? Other kids her age weren’t doing those sorts of things. Then you just put it down to every child’s different and that’s just the way she is………(A8)

From my experience, I guess with ‘sister’ she was just making more noises and more variety in her sounds and was attempting some basic words at that age of 12 months so I guess I was comparing her with her elder sister. (A1)

For all the mothers, in the UK and Australia, experienced or not, families’ daily conditions varied according to individual routines and they were alerted to baby behaviour that were different or unexpected. Mothers said they vacillated between thinking there was a problem, then not. Without fail, when their baby’s behaviour seemed normal on some days, they were reassured that they must have been previously mistaken. Mothers reported the following factors to explain why they could not decide. Four mothers said that their babies were placid; one mother said that even before six months of age that her baby was so placid that not even the loudest noise bothered her. Whilst these data suggest that being placid was acceptable on the one hand, on the other, a baby who was too good, an amazing sleeper, unaware or in “their own little world” was alarming.
Quite early I realised... she was..... she was just too good// Especially having a young brother....rampaging around the place.  (UK4)

..and you know everyone praises you for what a ‘wonderful sleeper’ you’ve got, such an amazing baby and you know..... I’ve gone from one child who couldn’t sleep even if you whispered to this child who could sleep through basically anything. So I had my suspicions then that there was something not quite right.  (A6)

One mother in the UK said her child was “lazy” and another in Australia described her baby as happy to “just sit around”. Five mothers in Australia, who had observed their child’s inconsistent responses to sound early, also said, conversely, that their children were smart, switched on, very alert, out-going and normal. Both inexperienced and experienced mothers were similarly alerted to baby behaviours that were different or unexpected. However, the degree of concern of the experienced mothers revealed another dimension. Their concern was framed by their experiences of what other siblings did and their expectation of their child in a context of all babies being different. When combined, the effect was to reassure mothers.

Reassurance was commonly offered within families. This was especially the case between the mothers and their own mothers in the UK and less frequently reported within the Australian family groups (2). In the UK, the four mothers who suspected a hearing problem called on their own mothers first, compared with only two mothers in Australia.

Only then.... we began to....ask people when she was 10 or 11 months old, I’d say to a friend, “Do you think she can hear us?” and they’d say, “Yes, yes of course she can. Look at that!” Yes, people who’d you know, had been around babies, and I’d ask my Mum and Dad.  (A1)

A response from one of the Australian grandmothers (A1) was that a hearing problem was unlikely as there was no family history, whilst another thought her daughter (A5) was “insane”. One Australian mother (A8), who lived away from immediate family, said that when she asked friends, they reassured her that her child needed more time as all children were different. She commented that
always living away from family meant, “you just get used to figuring things out on your own.”

In summary, mothers self-identified as either experienced or inexperienced and these data suggest that inexperienced mothers were none the less skilled than experienced mothers in responding to unusual or unexpected behaviour in their babies either before six months of age or later. In the case of inexperienced mother A3, the concern of an alert experienced health nurse working with her, shaped her action to facilitate a timely diagnosis for her baby. Otherwise, experienced mothers reported themselves as being more confident in their diagnostic capabilities, which shaped how they responded to their baby’s behaviour attributing unusual behaviour to a personality trait or accepting it as an individual difference. At first, all the concerned mothers, except for three, waited. They gave their babies the benefit of the doubt until there was no other possible explanation than that their babies had a hearing problem.

4.5 Preliminary professional responses to mothers raising concern
The quantitative data revealed variable patterns of delay for respondents in the period that elapsed from raising a concern about hearing to a confirmation of permanent deafness. Mothers’ accounts of their encounters with professionals, how they asked for help and raised their concern, provided insight into their experiences of this period of time. For some mothers, raising a concern with a professional resulted in a diagnosis at this point, which brought their concern to a natural conclusion. A third group are reported who were reluctant to raise concern. The results presented here are according to the country of origin. Reference to maternal experience/inexperience is made where it is relevant or relate to a mother’s actions and the next steps she took.

4.5.1 Mothers in the UK
All mothers in the UK were familiar with the role of a health visitor and for four UK mothers (UK2;UK4;UK5;UK6) a health visitor was the professional that mothers contacted. Three of these mothers variously described a health visitor as someone they knew in the context of “seeing them through” with another child and their existing relationship with a health visitor framed an expectation of help for these mothers in the UK. Two mothers (UK2 and UK4) approached
their health visitors before the time of a routine Health Visitor Distraction Test (HVDT) and mother UK4 said that knowing her health visitor meant that her concern was acknowledged.

Professional responses to a mother raising a concern about hearing were varied. For instance, health visitors dismissed the concerns of experienced mothers UK2 and UK4. It is noteworthy here, that at her postnatal check six weeks after birth, mother UK2 had already mentioned her concern to her family doctor, only to be reassured by the health visitor later that her baby could hear. To ascertain this baby’s hearing level, the health visitor presented sudden sounds and noted “eye blink” responses. Unconvinced, this mother sought a second opinion again from her family doctor, who told her to “stop it” because “she [the mother] knew that he [the baby] was alright”. The mother reported that after this encounter she continued to “watch[ed] him like a hawk and he wasn’t responding to anything” and she again asked for further testing. She reported that she adopted a confrontational position with the medical centre, where she phoned the health centre every day, resulting in a second health visitor being directed to visit her at home to “shut her up”. A second health visitor interpreted the baby’s responses very differently; she agreed with the mother that the baby did not respond to sound and made a referral to audiology services.

The health visitor’s response to mother UK4’s concern was to reassure her, test and retest her baby, even though the baby was not mature enough to perform the distraction test, according to the protocol. The mother referred to this early testing as the health visitor “fiddling” the process of distraction testing in order to give the test earlier. When the baby was old enough, the professional view of the baby’s test performance was that she was hearing well enough, which was not the view of the mother and she remained unconvinced. These results from the distraction test, albeit performed before the baby was developmentally mature, led the health visitor to reassure the mother again and tell her that she was being “over anxious”. Finally, for this mother and her baby, repeated distraction tests, over time, eventually convinced the health visitor that the baby had a problem and a referral was made.
Experienced mother UK3 had an older hearing-impaired child, who was not the adjacent brother of the new baby, so she told a different story. As professionals at her local health centre had dismissed her concern about an older child’s hearing loss, she chose to arrange a HVDT in another town when her baby was six months of age. This baby passed the HVDT.

Mother UK5, also an inexperienced mother, waited until her baby was mature enough for a routine HVDT to voice her concern. The health visitor said of the baby’s test results, that she was “fine” although a “little slow to respond”. She reassured the mother when she suggested that as English was not the family’s first language then this could account for the lack of response and babbling that the mother had noted. The mother said she was not happy with the results and insisted that an appointment be made for her baby to see an ear specialist. The health visitor reassured the mother again, commenting that “wax” might have been responsible for the baby not responding.

When inexperienced mother UK6 mentioned her concern about hearing to her health visitor during a routine postnatal check, the health visitor dismissed her observation as an “individual’ difference”. Whilst this reassurance was enough, at the time, to sustain the mother’s generalised view about the possibility of all babies being different, it did not reduce her concern about her own baby’s behaviour. Mother UK6 waited until the time of the HVDT, which was performed in the home. The mother said that her baby’s results were inconsistent; three sessions were needed to re-check and complete the testing. The mother considered her baby’s responses to be consistent with her own observations, made day to day, rather than those recorded by the health visitor. The mother insisted that her baby be referred for further testing, despite a pass result being entered.

At seven months of age mother UK3’s baby had passed the HVDT, nevertheless she became concerned by his lack of vocalisations and the fact that he was slow to talk. Although this mother knew nothing about a genetic component of deafness and despite her poor relationship with the local health clinic because of delays detecting her first child’s deafness, she deferred to professional opinion. The professional explanation for delayed speech development in her baby’s case
was twofold and reassuring for this mother. First, it was suggested that the baby had “glue ear”, and second, that the older deaf brother presented as a poor model for language skills and delayed speech could be expected in younger siblings. The mother said that she willingly accepted this reassurance, in the belief that first, the system could not let her down twice, and secondly, that a second child could not be deaf.

Inexperienced mother UK1 reported that she had been unconcerned about her baby’s hearing. However, when her baby failed the HVDT, she said that the health visitor reassured her by saying that her baby probably had a cold. The test was repeated and the mother and her baby were referred to “some sort of local specialist”, by which time the mother could see for herself that the baby had delayed speech development.

In summary, health visitors, generally, were involved in responding to a mother’s concern. Mothers in the UK group expected their babies’ hearing to be routinely tested and babies were tested more than once; on occasion, testing occurred before babies were developmentally mature. Reassurance was consistently offered to all mothers even when a baby failed the HVDT. Health visitors were responsible for referrals for further audiologic assessment and mothers negotiated changes to HVDT results when professional views of their baby’s test responses differed from their own to gain access to this testing.

### 4.5.2 Mothers in Australia

This section reports Australian mothers’ experiences of raising a concern with a professional. Unlike the UK mothers, Australian mothers’ accounts did not reveal either a special relationship with a particular child health nurse (health visitor) or a routine procedure for checking hearing. Professional responses to mothers raising a concern unfolded in ways that were predominantly individual. The data also disclosed a third category of experienced mothers who were reluctant to raise a concern.

All Australian mothers were concerned about their babies’ hearing at some stage and spoke to professionals at different times. Australian mothers were vague when they recalled early hearing checks, although one mother (A12) said her baby passed a check at eight weeks of age and another mentioned a six-
week ‘bell’ test, which her baby failed. Three mothers, A1, A5 and A10 raised a concern with a child health nurse and in two cases the nurses responded in similar ways. First, they reassured the mothers and they checked the babies’ hearing.

She [Child Health Nurse] was very vague and she did some clapping and so on… and ‘Baby’… errr…. sort of responded sometimes to the clapping. (A1)

…but I went and told the child health nurse. What she did, she went and got the bell, in front of him she stood and then she moved…she rattled the bell, she rang the bell and he followed her with his eyes. Then she said, “See he’s just probably used to all the environmental sounds in your house.”…. I mean he was seeing you. How could you say that he was hearing you, you’re meant to do it ……from the back, yeah? (A5)

Mother A1 said that when the child health nurse checked her baby’s hearing it became more obvious that her baby could not hear and she was responding visually or feeling a draught from movement. Yet the nurse reassured her. Retrospectively, this mother questioned the need for this type of reassurance in the light of her own clear concern about her baby’s lack of vocalisations and the behavioural evidence that she had reported.

I think if I asked the question, she said, “Ah well she’s probably OK. It’s a bit hard to tell. If she’s not better in a month… then, you know go and get her tested….. if you’re not convinced.” I think in retrospect, she should have said something like……I mean you know if you’re worried, you should take her and get her tested, at least it will give you peace of mind. I would have made that phone call a bit earlier. She sort of said, “don’t know,” and I was so ignorant and so convinced that she’s was fine and this wouldn’t happen to us. (A1)

Importantly, this mother commented that she was disappointed that the child health nurse did not respond more positively and acknowledge her concern. She said that had this been the case, she would have been prompted to take action earlier. However, the child health nurse put the onus on mother A1 to organise a
hearing test for her baby if she remained concerned. Making an appointment represented a second request for help for this mother, which proved to be difficult because of a holiday period and waiting lists. This baby was diagnosed with a profound hearing loss.

Mother A5 recalled that after the nurse had checked the baby’s hearing, the nurse said that the “house was very noisy”, in which case she suggested that it would be difficult for the mother to accurately assess her child’s responses. Unconvinced by the reassurance, the mother took a second opportunity, when her baby was hospitalised for suspected meningococcal disease, to ask a paediatrician to arrange for a hearing test.

I saw the doctors when we got up to the ward when they came and told me that there was nothing to worry about, it’s just a viral infection that did this to him, and I said I had a concern about his hearing and they asked why I had a concern. So I said about closing the doors and calling his name, he just doesn’t listen. Yes, and then….that’s when they spoke to the audiologists there and they sent me an appointment for a screen. (A5)

As a result of this chance referral, the baby was diagnosed with a profound hearing loss.

Mother A10, a nurse, was concerned about her baby and she decided to wait for a routine developmental assessment, because her previous experiences of asking for help from either a paediatrician or a child health nurse had been awkward and unsupportive. She became uncomfortable when she was telling her story as she admitted that she did not have a “rapport with anyone really”. She reported that this was a result of an earlier problem when breast-feeding was difficult to establish. She had consulted her baby health clinic and a paediatrician to ask for help. The paediatrician told her that it was “a nonsense, every mother can breast feed” and that she needed to go home and “get your [her] act together.” As a result, when mother A10 needed to raise a concern about hearing later, she waited until a routine baby health check. Her concern was dismissed because the child health nurse preferred to focus on her child’s delay in walking. Although this mother continued to be concerned about her baby’s lack of speech
development she said that she avoided the health centre and sought assistance from a private audiologist. Mother A10’s baby was diagnosed with a permanent hearing loss.

Five mothers A2, A6, A7, A11 and A12 raised concern with family doctors who responded to them in the following ways. Experienced mother A2 used a current paediatric referral for a vision problem to obtain a hearing test that resulted in a diagnosis of hearing loss. Mothers A6 (experienced) and A11 (inexperienced) said that their family doctors gave them a referral to a specialist audiology centres. Experienced mothers A7 and A12 consulted their family doctors. The doctor observed A7’s baby and used a tuning fork to test her hearing and reassure the mother that the baby was fine. The doctor suggested that the mother monitor the situation and come back in six months. This message of reassurance and a ‘wait and see’ approach failed to convinced her that she should not be concerned because her baby was now strangely quiet and generally unaware. At a music kinder gym, her baby failed to attend to any sound and as the baby matured, evidence of her baby’s hearing problem became substantial when no babbling or speech sounds emerged. Mother A7 waited as directed, intending to follow the advice of her doctor, until the point was reached when it was obvious that the baby could not hear. She returned to the doctor who referred them for further auditory investigation, which resulted in a diagnosis of a hearing loss. Similarly, mother A12 consulted her family doctor around six months of age, who “checked his ears”, although this mother did not say what this involved. Convinced of a hearing problem, she consulted a private audiologist when he baby was aged thirteen months and a profound hearing loss was diagnosed.

In summary, Australian mothers consulted either a child health nurse or their family doctors and professional responses to concerns raised about hearing were individual and irregular. Of four mothers who talked first with a health nurse, each story revealed an encounter which shaped three different responses and these were 1) an alert nurse who encouraged the mother to seek a hearing test because of risk factors despite contrary medical reassurance, 2) a dismissive nurse, (two cases), 3) a dismissive nurse who saw no need for urgency yet suggested that if concern continued then the mother needed to organise a
hearing test. Of four mothers who raised a concern with a family doctor, one was reassured and told to wait and three were referred, one baby (A1) for vision and two (A6 and A11) for hearing.

Diagnosis as a next stage event, as the result of a preliminary professional response to a mother’s concern, occurred in six cases (50%). These were, case A1, a mother who eventually referred herself, cases A2 and A7 after a period of waiting, case A5 by chance and cases A10 and A12 through mothers’ self referral to private audiology services to avoid child health referral systems. Diagnoses were obtained for these mothers because of their confidence about the evidence they had of their child’s behavior and their determination in seeking further audiologic assessment. Four of these mothers were experienced.

4.6 Mothers reluctant to raise a concern and babies with otitis media with effusion conditions (OME)

Three experienced mothers were in this category, A8, A4 and A9. Mother A8 was reluctant to raise a concern because she said that her youngest child’s behaviour was difficult to define. She was disinclined to ask a professional about this behaviour as her friends had convinced her that firstly, her baby needed more time, and secondly, each baby was different. Notwithstanding this reassurance, she was accustomed to working things out for herself in the absence of close family support.

For these mothers, the context in which they raised a concern was medical and their children’s conditions complex yet, they told similar stories. Both mothers A4 and A9 were nurses and their babies had histories of otitis media with effusion (OME) and their treatment was managed by ear nose and throat specialists (ENT). The mothers said that their babies’ failure to babble was consistent with what they expected from babies with this condition and neither mother was unduly concerned in the first twelve months. Mother A4 reported that whilst her baby failed a routine distraction test at the child health centre, constant ear infections prevented her from returning for a follow up appointment because her baby was never well enough to do the test. At that time, from this mother’s perspective, she saw no reason to raise the matter of her increasing concern about her baby’s lack of babble and vocalisation because
it was more or less what she expected with the condition, in spite of surgery for
the insertion of ventilation tubes and medical supervision.

Mother A9 said that she had been concerned about hearing before her baby was
twelve months old and the concern was constant. She had always felt her child
was unable to understand what she said and she consulted a speech pathologist.
Nurse colleagues reassured her that hearing tests with small children were
unreliable and with the support of a speech pathologist, she reported that it was
easier to believe that her child only had a speech problem.

Both mothers A4 and A9 reported the effect of medical opinion, which
influenced their acceptance of delays in their child’s speech and language
development and their failure to raise a concern. For mother A4, even with her
experience of raising four children and her medical background, she found it
surprising, in retrospect, that she had accepted unreservedly that grommets were
what was needed and that she “took one person’s opinion that it [lack of speech
development] was all alright.”

……and when I think I was a fourth time parent, a nurse for 16 years
and you know I’m not silly yet I was so naïve to all of that information
the difference…a conductive and a real…. [hearing loss] because it
wasn’t you know…..out there? Nobody said anything.

(A4)

Mother A9 had an older child who had been slow to talk which also influenced
her decision not to raise a concern. Notwithstanding her lowered expectations in
this regard, she held the belief, supported by her nursing colleagues, that
grommets would fix her child’s chronic otitis media condition and the speech
delays would resolve.

……and so you know a nurse,… so all medical people, and she said
that you’ll notice a big difference when the grommets go in. But we
didn’t. (A9)

For these mothers, medical information and advice combined with their
personal understanding of conductive hearing loss, the benefits of surgery and
experience of their other children provided a complex context in which to raise
A summary of mothers' concern and preliminary professional responses in the UK and Australia is shown in Tables 4.3 and 4.4.

Table 4.3 Summary of professional responses to mothers' concern.

devolutional checking and distraction testing in the UK.

<table>
<thead>
<tr>
<th>Mother</th>
<th>Concern</th>
<th>Developmental Check 6 wks</th>
<th>Distraction Test @ 7 mths</th>
<th>Received reassurances?</th>
<th>What was said</th>
<th>Convinced</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK1</td>
<td>No</td>
<td>Fail HVDT</td>
<td>Yes, by health visitor</td>
<td>He’s got a cold that could be stopping him</td>
<td>Yes</td>
<td>10 mths</td>
<td></td>
</tr>
<tr>
<td>UK2</td>
<td>Yes</td>
<td>Pass</td>
<td>Pass HVDT delivered early then failed</td>
<td>Yes, by family doctor @ 8wks, also from health visitor</td>
<td>Stop worrying, look he blinked. He’s got a cold.</td>
<td>No</td>
<td>10 mths</td>
</tr>
<tr>
<td>UK3</td>
<td>Yes</td>
<td>Pass HVDT</td>
<td>Yes, by health visitor</td>
<td>Could be ‘glue ear’ but brother is deaf, so this child will be slow to talk</td>
<td>Yes</td>
<td>18 mths</td>
<td></td>
</tr>
<tr>
<td>UK4</td>
<td>Yes</td>
<td>Pass HVDT delivered early then failed</td>
<td>Yes, by health visitor</td>
<td>You’re doing OK, you’re over anxious</td>
<td>No</td>
<td>10 mths</td>
<td></td>
</tr>
<tr>
<td>UK5</td>
<td>Yes</td>
<td>Pass HVDT</td>
<td>Yes, by health visitor</td>
<td>She’s fine. Slow to respond because English is not your first language. Maybe wax</td>
<td>No</td>
<td>14 mths</td>
<td></td>
</tr>
<tr>
<td>UK6</td>
<td>Yes</td>
<td>Pass HVDT</td>
<td>Yes, by health visitor</td>
<td>All babies are different. Look she’s fine</td>
<td>No</td>
<td>10 mths</td>
<td></td>
</tr>
</tbody>
</table>

their increasing concern. A summary of mothers' concern and preliminary professional responses in the UK and Australia is shown in Tables 4.3 and 4.4.
### Table 4.4 Summary of professional responses to mothers’ concern, developmental checking and distraction testing in Australia

<table>
<thead>
<tr>
<th>Mother</th>
<th>Concern Yes/No</th>
<th>Developmental Check 6 wks</th>
<th>Distraction Test @ 7 mths</th>
<th>Reassured?</th>
<th>What was said</th>
<th>Convinced Yes/No</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
<td>Yes</td>
<td>Pass</td>
<td>No test</td>
<td>Yes</td>
<td>child health nurse</td>
<td>Yes</td>
<td>15.5 mths</td>
</tr>
<tr>
<td>A2</td>
<td>Yes</td>
<td></td>
<td>No test</td>
<td>No</td>
<td></td>
<td>Unsure</td>
<td>5.5 mths</td>
</tr>
<tr>
<td>A3</td>
<td>No</td>
<td>Risk factor concern</td>
<td>No, ABR @ 6wks</td>
<td>Yes</td>
<td>obstetrician</td>
<td>No</td>
<td>2 mths</td>
</tr>
<tr>
<td>A4</td>
<td>Yes</td>
<td>Test / fail</td>
<td>Yes, by family doctor and ear nose throat specialist</td>
<td></td>
<td>It’s only fluid. We’ll put grommets in.</td>
<td>No</td>
<td>15.5 mths</td>
</tr>
<tr>
<td>A5</td>
<td>Yes</td>
<td>Pass</td>
<td>No test</td>
<td>Yes</td>
<td>by child health nurse</td>
<td>No</td>
<td>5 mths</td>
</tr>
<tr>
<td>A6</td>
<td>Yes</td>
<td>Test / Pass</td>
<td>Referral from family doctor; Yes, by audiologist</td>
<td>Not concerned; come back in 6 mths when Eustachian tubes are open</td>
<td>Yes</td>
<td>15.5 mths</td>
<td></td>
</tr>
<tr>
<td>A7</td>
<td>Yes</td>
<td>No test</td>
<td>Yes by family doctor using tuning fork @ 10 mths</td>
<td>She’s fine. Keep an eye on it, wait and see. Come back when she’s 12 mths old.</td>
<td>Yes</td>
<td>11 mths</td>
<td></td>
</tr>
<tr>
<td>A8</td>
<td>Yes</td>
<td>Pass</td>
<td>Test / Fail</td>
<td>Yes</td>
<td>by audiologist</td>
<td>No</td>
<td>33 mths</td>
</tr>
<tr>
<td>A9</td>
<td>Yes</td>
<td></td>
<td>No test</td>
<td>Yes</td>
<td>by ear nose throat specialist</td>
<td>Grommets will make a difference</td>
<td></td>
</tr>
<tr>
<td>A10</td>
<td>Yes</td>
<td></td>
<td>No test</td>
<td>Yes</td>
<td>by child health nurse</td>
<td>Yes</td>
<td>15.5 mths</td>
</tr>
<tr>
<td>A11</td>
<td>Yes</td>
<td>Test / Pass</td>
<td>Referral from family doctor; Yes, by audiologist</td>
<td>Baby has a cold; come back in 6mths.</td>
<td>Yes</td>
<td>9.5 mths</td>
<td></td>
</tr>
<tr>
<td>A12</td>
<td>Yes</td>
<td>Pass</td>
<td>No test</td>
<td>Yes</td>
<td>family doctor @ 6mths</td>
<td>Yes</td>
<td>15.5 mths</td>
</tr>
</tbody>
</table>
4.7 **Referrals, delay and diagnosis**

In response to the question about where the diagnosis took place, quantitative data show that typically a diagnosis of hearing loss was not achieved in one setting, rather respondents checked a combination of settings in both countries. The UK respondents identified audiology clinics and/or local or city hospitals as the places they went to next and this was confirmed in the interview data. Mother UK4 said the referral that followed her baby’s failed HVDT was for a “routine hearing test”. She said that she believed that this second test was more or less something that everyone did and a permanent hearing problem was unlikely. The health visitor reassured the mother when she said, “she’ll be OK, you know”. The mother said that the routine hearing test used a “sound box” with equipment to record results that confirmed her baby’s hearing loss. Inexperienced mother UK6 reported her confusion about the referral for further testing to an audiology clinic at a local hospital. For this mother the hearing test was performed in a similar way to those conducted by the health visitors in her home and she said that she needed to go back several times before a result was recorded. All the UK mothers, referred by health visitors for further audiological testing, said they received a diagnosis.

Quantitative data from Australian respondents identified health centres, Base Hospitals, children’s hospitals or specialist paediatric audiology clinics. In the interview data, four Australian mothers also named specialist paediatric audiological centres that were located within early intervention programmes for hearing impaired children and the Australian mothers generally said they had a second referral to a different paediatric setting to confirm preliminary audiological results. All the mothers in Australia talked about Australian Hearing and some mothers said their children were re-tested there.

Mothers A6 and A11 were referred to an audiology clinic. Although one mother was experienced and the other was not, neither mother had a sense of a permanent deafness and the experiences of the mothers were similar. Experienced mother A6, recalled that she observed her baby to make no response to sound during the test in this clinical setting. The mother reported that she heard the audiologist say that the baby’s Eustachian tubes were closed.
and she remembered having “no idea” what that meant. However, overall she took it to mean that her baby needed more time.

She didn’t have any clear responses to just the sound presentation, so it was just the vibration stimulation; but they didn’t say that to me they basically didn’t tell me anything. They just more or less said that being 8mths old and her Eustachian tubes hadn’t fully opened and they were unclear about the reading and as she had an ear infection as well, they said ‘look we are not overly concerned but we would like to see her again when she is 12 mths old and that would allow the tubes to fully open…’

(A6)

Although mother A11 was inexperienced, she believed that she had an appointment for a routine hearing test; retrospectively she learnt that only middle ear function was measured and no test for hearing loss was performed on that day. She did not ask questions at the time and being unfamiliar with hearing tests, she said “[we] just thought that must be what happens at those tests”.

Well we didn't really think at that stage that there was any problem because they didn't explain at this stage what they'd really done. And they asked if she had had a cold recently and we said 'she had' and they said, ‘Oh well when they've got colds … that results aren't always that accurate so leave it for 6 months and come back.’ It didn't really leave us with any thoughts that it would possibly be anything. We just thought you know, that must be what all kids are sort of like and if they've had a cold then you know what you're like yourself if you've had a cold sometimes then you can't hear everything. (A11)

In both cases, these mothers reported that after their referral to an audiology clinic, and following testing, a professional response from an audiologist was that they needed to ‘wait and see’ until their baby was twelve months old.

Mother A6 said that the four months she waited and watched her baby being unresponsive to sound was a “long, long, long four months of waiting”. She said that returning to the hospital for re-testing was a similar scenario to the previous one but that the test results and outcome were more confusing.
I mean when I look back and think what her (the audiologist) reaction was, she… there was no clear eye contact and basically she was very quiet and didn’t provide me with pretty much any information, and just said, ‘look I’d like to make an appointment for you to go and see the specialists at the ‘different hospital’ and they can re-do the tests. She didn’t give me any diagnosis at all as to whether my child could hear at all so again I walked away basically not knowing. (A6)

Mother A6 made her own appointment within a week at a specialist hospital, and a third assessment resulted in a diagnosis of permanent hearing loss.

I think it was and within five minutes of just….you know…doing some sound field testing …. ‘Child’ was just thrown in the room and they put some noises and they would bang drums and get all the toys and rattle them and she just sat there and you know played by herself and she [audiologist] said “I don’t even think we need to go and do any audiometric testing because its fairly evident she’s not hearing virtually anything.” I think it was like in about 3 to 4 minutes the lady just turned around and said, “What do you think about your daughter? What would you say her hearing loss is? “I said “Look it’s pretty severe” and Husband said “I don’t think it’s that bad” and she just broke the news to us and said, ‘your daughter has a profound hearing loss. (A6)

Although mother A11 said her memory was vague about dates and times, she said that she did not wait for the full six months recommended by the audiologist as her baby developed an ear infection. She consulted an ENT who managed the condition with medication. Some time later, the family needed to go away and the mother said that she knew vaguely that there was “something about kids with their ear infections and airplanes” that motivated her to question the ENT. S/he responded with some testing and further audiological investigation, and a diagnosis of a profound hearing loss was made.
I don't know what all the tests are I'm guessing it was all the same equipment that they use now for the pressure tests so I'm guessing it was a pressure test and he didn't really like what he saw. There seemed more…. // We knew something...was a bit up with him [the audiologist] but obviously he didn't want to say one way or another because he didn't know ...one way or the other. So that's when we got referred to the ‘different hospital’, and they gave us the diagnosis that ‘yes she had fluid on her ears’ and that she had more than just fluid on her ears. So we went into that appointment thinking that she has fluid on her ears and this is what happens to most people and she'll get it drained off and then she'll be able to hear and that's when we sat us down and said she won't be able to hear even when they drain it off so.....there it was (A11)

Referrals from general practitioners to audiology clinics for both of these mothers produced a ‘wait and see’ response. For one mother her child’s ear infection provided an opportunity for a chance referral for further testing whilst the degree of concern for the other mother escalated and she returned to clinic sooner than directed. Professional responses, on the second occasions, were for further investigation and a third round of testing, which resulted in a diagnosis of permanent hearing loss in both cases. In summary, for these mothers, rather than a flow of systematic referrals, these results revealed a stop/start pattern of stages where mothers’ own initiations of interactions emerge as central to maintaining the momentum between the stages.

4.7.1 The reluctant mothers and the effect of OME on a diagnosis
Although mother A8 reported that her baby had failed a distraction test, she did not remember being asked to return with any sense of urgency. Notwithstanding the failure of a follow-up appointment, this mother reported that family events overtook her. Importantly, she stated that she did not think the situation was serious.
……even though she failed it [the hearing test] the people who did the testing in City weren’t saying, “this is serious you need to …” they just said, “Yes she does need to be re-tested but she could just be cranky and tired,” because I had been shopping for several hours prior. So even when they said about the re-testing they didn’t say it was serious…//….. and I certainly didn’t feel that I should rush back next week and get it done. So yeah…. So it did get left; and then once we moved with the unpacking and the new house and settling in it just sort of got left for quite a while then we did start to observe other things, yeah…

(A8)

In her baby’s second year, after a series of ear infections, the family doctor diagnosed a conductive hearing loss and a referral was made to an ENT who organised surgery for the insertion of grommets and organised a hearing test under general anaesthetic. Mother A8 said that this test revealed a severe/profound permanent hearing loss when the child was 30 months old.

Mother A4 reported a confusing sequence of events after her baby’s myringotomy. She said that unknown to her a full audiological assessment performed during the surgery under general anaesthetic had revealed that her baby had severe sensorineural component to his hearing loss. According to the mother, a conflict arose because the surgeon’s staff and the hospital audiologist, aware of the diagnosis of a permanent hearing loss, believed that the mother had been informed. After her baby’s surgery this mother was alarmed by a casual remark made by the ENT as was leaving the consulting room with some medication. She was asked if her baby had his hearing aids from Australian Hearing. Until this time there had been no mention of permanent deafness. Acting on this new information the mother made an appointment at Australian Hearing in keeping with the ENT’s suggestion. Over the following weekend, the mother reported that the medication appeared to make a difference and her baby started to babble and vocalise and she said that she felt relieved because she had been very concerned. However, she still took the baby to Australian Hearing where she discovered
that ‘Baby’ couldn’t hear as he didn’t flinch even when these loud sounds that were hurting our ears were presented. The audiologist used the word profound together with the word hearing loss and we had no idea that this was a term that meant so much but we could see that this was serious. (A4)

For mother A9 and her child, a diagnosis of sensorineural hearing loss came on his third birthday after one year of speech pathology. This baby was diagnosed with a Mondini condition and enlarged vestibular aqueduct, which possibly accounted for his deteriorating hearing condition. However the mother reflected on the professional responses that promote the “myth” of grommets that sustain parents’ expectations of ventilation tubes when babies are slow to develop speech and language.

So that’s what I’m saying he [ENT] never alluded to that [there might be no change] it was only a colleague at work who said to me you should have noticed a change by now. No, but we didn’t and when I spoke to the specialist in City he said you don’t always see a change. So that’s what I’m saying it’s a bit of a myth. But I didn’t know. (A9)

However, she also expressed a view that she had done everything she could with the information she had. In summary, a diagnosis for these three mothers occurred only after ineffective communication of results to mothers and inadequate follow-up in two cases.
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4.8 **Concern about a hearing problem: Australia - NHSP cohort**

In Australia, in the NHSP cohort, a hearing screener was the first person most likely to suspect a hearing problem in babies younger than six months of age and this is illustrated in Figure 4.7.

![Figure 4.7](image)

**Figure 4.7 Australia (NHSP): Person most likely to suspect a hearing problem in babies younger than 6 months**

However, mothers still played a part in suspecting hearing loss in three cases even after babies’ hearing had been screened at birth. The same calculations were performed for the NHSP cohort as with the non-NHSP grouped to show the delay between flagging a concern about hearing and confirming a hearing loss. These results for the total Australian NHSP cohort are presented in Figure 4.8.
Figure 4.8 The time between concern and receiving confirmation of a hearing loss for Australian mothers with babies screened at birth
4.8.1 Time between raising concern and diagnosis (NHSP)
Quantitative data from this cohort showed regular patterns of short delay. Long delay patterns were noticeable from five babies screened at birth.

4.8.1.1 NHSP cohort — Short delay pattern (n=17)
In this cohort, the data revealed 17 babies with short delay patterns, where a concern was raised soon after birth followed by a diagnosis. One baby, not screened until five months, was shown to have a short delay pattern, which possibly suggests a sick baby.

4.8.1.2 NHSP cohort — Long delay pattern (n=5)
Unexpectedly, five babies, (cases 33; 40; 43; 44; and 47), were recorded in this cohort with long delay patterns. Two babies, cases 40 and 43, were screened at birth with a diagnosis occurring at 16 months and five months respectively. The data show that three babies, cases 33, 44 and 47 in this group, appeared not to have been screened at birth. For a mother to select this group, she must have believed that her baby was screened irrespective of the outcome. There are three ways that possibly account for this long pattern of delay in these cases. First, the infant may have passed the newborn screen and developed a hearing loss later. Second, the screen may have recorded a false negative and the baby was in fact hearing impaired. Third, the baby may have been referred and the mother failed to return for further testing for whatever reason.

4.9 Mothers and a newborn hearing screening programme
There were six mothers in this cohort and the individual case data are presented in Figure 4.9.
Figure 4.9  *Time taken from raising a concern to confirmation of hearing loss for mothers in the selected NHSP sample in Australia (n=6)*

Table 4.5 illustrates maternal experience, according to the classification previously used, and a mother’s knowledge about a programme to screen the hearing of newborn babies.

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Experienced</th>
<th>Prior knowledge about newborn screen</th>
<th>Newborn screen</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1/scr</td>
<td>No</td>
<td>No; on day of discharge</td>
<td>Yes</td>
<td>fail</td>
</tr>
<tr>
<td>A2/scr</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>fail</td>
</tr>
<tr>
<td>A3/scr</td>
<td>No</td>
<td>No; after birth of baby</td>
<td>Yes</td>
<td>fail</td>
</tr>
<tr>
<td>A4/scr</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>fail</td>
</tr>
<tr>
<td>A5/scr</td>
<td>Yes</td>
<td>Not known</td>
<td>Yes</td>
<td>pass</td>
</tr>
<tr>
<td>A6/scr</td>
<td>Yes</td>
<td>No; Nurse took baby whilst mother was sleeping</td>
<td>Yes</td>
<td>pass</td>
</tr>
</tbody>
</table>

The interview data revealed that before the birth of their babies, four mothers were unaware of a test to screen the hearing of newborn babies. Three mothers said they were aware of post-natal assessments for babies such as the heel prick
test or checking for hip dislocation and one mother said she was aware of screening for hearing loss in the context of a family history, which confirmed she had a prior understanding of ‘at risk’ screening.

No, so that [newborn hearing screen] was sort of an unexpected thing so I just took it very lightly. It’s not something that you tend to expect that there would be a problem, not being in the family, so you just went along with it.  (A1/scr)

The hearing screen was introduced to the mothers at different times during their immediate post-natal period in hospital. The following quotations illustrate how mothers came to know about a newborn screen for hearing loss.

It was fairly general really, the screening probably could have been done on any day prior to being discharged, it was just one of those last minute things that had been mentioned to me on… actually I think it was on the day of discharge that I needed to go and do a hearing test on my baby; that's something that I wasn't aware...  (A1/scr)

No, not specifically [talked about] like the other tests were, but no the hearing test wasn't, I didn't even know that it was going to happen. // The day after she was born and as you can imagine I was still pretty overwhelmed, first child, new baby… and thinking ‘what is [emphasis] going on here?’ basically the lady just came in, hooked her up and did the screening test. I’m not sure that I even remember very much about it.  (A3/scr)

Yes they'd said to me that everything went fine…What?……I didn't.... when they did the newborn hearing screening test I wasn't there. They just came into the room and they said that she's going for this test can ...I....we ...she's asleep can I take her? We won't be so long rah rah rah...so…and I was actually left in the room and they took her and did it wherever they did it.  (A6/scr)

4.9.1 Mothers and their newborn hearing screening results
Mothers A1/scr, A2/scr and A3/scr were all inexperienced mothers and their babies failed the hearing screen. Experienced mother A4/scr did not report the screen test result other than to say that her baby was screened. Experienced
mother A5/scr’s baby was re-screened before discharge because of an inconclusive result for his left ear and a pass result was recorded and mother A6/scr, also experienced, had a baby with a pass result. All the mothers said they understood ‘pass’ and ‘fail’ in a screening context. Mother A3/scr referring to herself as a ‘health practitioner’ said that she was aware of the nature of screening for any condition and the meaning of false positives or negatives. This characterised how she understood the events that followed for her baby compared with other mothers in this cohort. Mothers reported a variety of terms that screeners used to explain a test results, which included, ‘refer’, ‘inconclusive’, ‘both ears are not passing’, ‘a bit of a question over the left’, ‘repeat to be sure’, ‘we’ll try again tomorrow’. Table 4.5 presents a résumé of what was said to mothers after the first hearing screen.

<table>
<thead>
<tr>
<th>Mother</th>
<th>What was said</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1/scr</td>
<td>Not actually a pass result; you need to book a retest in a couple of days.</td>
</tr>
<tr>
<td>A2/scr</td>
<td>It's a fail on both ears; this often does happen with some babies; it's fluid in the ears… you don't need to go and learn sign…</td>
</tr>
<tr>
<td>A3/scr</td>
<td>She's either passed or it's inconclusive; a number of reasons for inconclusive; she could have fluid in her ears, or some other reason; her hearing could still be fine but something blocking.</td>
</tr>
<tr>
<td>A4/scr</td>
<td>Not reported.</td>
</tr>
<tr>
<td>A5/scr</td>
<td>The left ear didn't pass; come back tomorrow and we'll try again.</td>
</tr>
<tr>
<td>A6/scr</td>
<td>Everything went fine; we thought you might like to keep these [plastic ear muffs].</td>
</tr>
</tbody>
</table>

Four mothers, A1/scr, A2/scr, A3/scr and A5/scr reported that their babies were screened more than once, first before discharge, after which two mothers A2/scr and A3/scr said they returned to their birth hospitals for a third screen.

The mothers’ stories unfolded differently after the first screen failure. Mother A5/scr said although her baby had a pass result, she remembered that “it [the printout] still took a little while” and when pass result was given, the screener said, “Ah, there you go, cool!” This mother added that when her child was
confirmed with a hearing loss much later, the ENT told her that a “slow or inconclusive” result must always be referred for further audiologic testing.

The mother of baby A1/scr said when she returned to the birth hospital a few days later the results for her baby were the same. Her baby failed and a refer result was recorded. This mother said that even though the screener explained the conditions that could cause a ‘fail’ result and offered her reassurance, she was still worried because the screen tests were not able to say how severe the problem was. She said the referral was largely “unexplained” and the “not knowing” was an anxious time.

Reassurance worked well for mother A2/scr after a second screen fail as it focused on a likely explanation being “fluid in the ears” and so she was able to go home, establish breast-feeding routines and not worry. Indeed, she added that she was not suspicious of a problem at all. Mother A3/scr, who was familiar with screening procedures, returned for a third screen. She reported that an inconclusive result had a meaningful fit with her understanding of the process and the tone of the reassurances she received from the screener was appropriate. Although a third test flagged the need for definitive testing, the mother was optimistic, as she saw no reason that might indicate a potential problem and she knew that babies were unpredictable. Her observations of her baby’s responses convinced her that her baby could hear.

It is noteworthy to record here, that two mothers experienced a complicated flow of early events. These were, mother A12, from the non-NHSP cohort and mother A4/scr. According to her account, mother A12 from the Australian non-NHSP cohort believed, on discharge from hospital, that her baby had been screened at birth. She said she had been aware of the policy to screen babies at birth and she understood this to have occurred with her own baby after his birth. Unknown to her, the equipment had not been working on the days she was in hospital and all the babies born during that period were referred and recalled for screening to a different hospital. This mother said she did not receive a letter and only discovered thirteen months later, when she had another baby, that the equipment had been broken down for over a year and babies were not being screened. Mother A4/scr’s baby was screened at birth and failed. Unknown to
this mother, further objective testing, Auditory Brainstem Response (ABR), had occurred in her birth hospital and a hearing loss had been confirmed. However, the results had been “misinterpreted”, filed away and the mother uninformed.

In summary, not all the babies that were screened for hearing loss at birth were identified. Of the three mothers with a screen fail and refer result, two said they were not anxious or concerned that their babies could have a permanent hearing loss. Four mothers, A4/scr, A5/scr, A6/scr and A12 (Australian non-NHSP cohort) were discharged from their birthing hospitals, believing their babies to have been screened and hearing within normal limits. All these mothers suspected a problem with hearing at a later date and these data were analysed separately, as a group.

4.10 Mothers, newborn hearing screen fail, referral and pathways to diagnosis in the NHSP cohort (Australia)

For three mothers with babies in the NHSP cohort a newborn hearing screen ‘fail’ resulted in an automatic referral to audiology services. In this sense the referral pattern could be viewed as comparable with the UK mothers whose babies failed the HVDT, in so far as hearing screening test results generated an automatic referral for further testing.

Interview data revealed that three mothers A1/scr, A2/scr and A3/scr and their babies were referred within three weeks for further audioligic investigation resulting from two or three newborn hearing screen failures. Mothers commonly referred to this testing as “an ABR”, which took time and involved mothers nursing their babies. One mother (A2/scr) was unconcerned by the nature of the recall. She believed her baby to be fine and she described further audiological testing as “just one of those tests you have to do” and this remark resonates with mother UK4’s remark about going to a “routine” test situation. A second ABR was organised for this mother a week later to confirm the results and she was asked to prepare any questions she might have as an ENT, speech pathologist and a social worker would be available at the time of the second test to answer her queries. Similarly, Mother A3/scr was also unconcerned at the time of the referral for further audiologic investigation. She reported that the newborn hearing screener accompanied her to the audiology centre for the appointment. This mother said that she felt that the audiologist conducting the testing had
difficulties in delivering the news of her baby’s hearing loss to her. However, the screener, who was an experienced worker in this situation, reported the results with appropriate sensitivity and was supportive. Three mothers with babies who failed a newborn hearing screen were all diagnosed with a hearing loss.

4.10.1 Preliminary professional responses to mothers concerned later about the hearing of babies already screened at birth

Three babies were screened at birth without a refer result. Their mothers told how they later became concerned about their babies’ behaviour. Referrals to audiology services for mothers wanting to raise a concern about hearing in their babies screened at birth, but not identified, were more complicated to achieve.

Mother of baby A4/scr and a professional in the field, recognised that her baby did not have the range of expected speech sounds at six months of age and she became concerned. She consulted her family doctor, obtained a referral to a paediatrician and a hearing test was arranged. Unfortunately, the mother said, the test needed to be abandoned as her baby became frightened. The lighting was poor, the seating, a high stool was unsuitable for a young child and he was unable to recover enough to complete the hearing test in the booth. The mother said that her professional understanding of the impact of a hearing problem made re-testing a matter of urgency for her and she tried to rebook the test. As the family lived more than six hours from any audiology services, it required special organisation on her part to rearrange. Similar to mothers in the non-NHSP cohort, and in spite of her professional background, mother A4/scr reported that she failed to convince professionals of her concern and that the situation for her baby was urgent. The following quotation encapsulates her feelings after the failure of a preliminary appointment for her baby and her efforts to obtain a second timely referral.
There wasn’t… a great sense of urgency… to you know.. to get like another…. when he failed one of the ….you know free field tests … there was no sense of urgency to try to get him in and try and get the next one re-attempted. It was just like well you know we’ll send you an appointment, and I live 6 hours from ‘State capital city’ and you know I was the one saying ‘look please can I try and coordinate this? if you’re just going to post one out in the mail then at least try and make it around the time….that….’ but you know I had to do all that work at trying to co-ordinate it rather than have another wasted 6 hour trip to ‘City’, but you know there was just no sense of he’s a nine month child, we should prioritise him and just get him in soon and get to the bottom of this you know?  

(A4/scr)

The nature of an initial professional response to mother A4/scr’s concern about the failure of the first test was that her baby was “developmentally not ready to do the free field test”. Retrospectively, during the interview, this mother tried to understand and justify why she gave up trying to convince professionals of the urgency of her baby’s problem.

It’s funny, looking back I was not as demanding as I… looking back I think why didn’t I jump up and down more? I think I was just so caught up in …..(long pause, tape stopped. Mother continued after a break) …erm I’d gone back to work and I was trying to commute to State capital City’ to all these appointments and commute to work, and I think I was so overwhelmed with what I was doing in my life that I wasn’t being assertive enough and going and demanding and trying to hurry things along or whatever….I just went along with the flow.  

(A4/scr)

Mother A5/scr said that at approximately nine months of age, day-care staff noticed that her baby was unconcerned by sudden loud sound and not easily roused when sleeping. The mother said that staff questioned her and she responded that her baby had been screened at birth and she was unconcerned because he turned to sound at home. Nevertheless, the mother started to monitor the baby’s responses and observed, on occasion, that he seemed unresponsive. She said that she decided to have his hearing checked. She obtained a referral and consulted an ENT who diagnosed “glue ear”.

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Mother A6/scr questioned her baby’s behaviour on two counts. First her baby’s lack of response to sudden loud sound and second, the fact that she became distressed and inconsolable whenever her mother was out of sight. Similar to other mothers in the non-NHSP cohort she voiced her concern first with family, then she asked friends for an opinion. When her baby was six months of age she raised her concern with a child health nurse who responded by checking the baby’s hearing. The mother believed the test to be similar to the hospital screen test as she recognised the little “earmuffs”. The child health nurse could not achieve a result and she blamed the machine, saying it had been “playing up lately”. Nevertheless, the child health nurse said the baby was fine. Although, at the time, this mother also mentioned her concern about her baby “tuning out”, which seemed not to be connected to hearing, she was reluctant to question the results of the test which she had seen for herself.

During the following year, as her concern increased, this mother reported obtaining referrals for hearing tests from the child health clinic and later went to Australian Hearing. However, her child became increasingly difficult to manage in any unfamiliar situation to a point that using puppets to condition her response to sound became impossible. Similar to A4/scr, this mother also gave up. As time went on and speech and language failed to develop, others began to share this mother’s view that the child could not hear. Professional childcare staff focused more on her child’s personality, which they described as stubborn or awkward and her social behaviour as “disconnected to people”. This mother reported that she was relieved when, supported by these staff, her family doctor gave her a referral to an ENT.

In summary, these data revealed that mothers A4/scr, A5/scr and A6/scr shared a similar trajectory of events to the mothers who raised a concern in the non–NHSP cohorts. Two mothers experienced difficulty encouraging a professional response consistent with their level of concern and the symptoms they described. Both mothers sensed the situation to be urgent which contrasted with the professional view that the children were difficult to test. The professionals accordingly attached labels other than hearing loss to explain the problem and poor test responses.
4.10.2 Diagnosis for mothers with babies screened, but not identified at birth

Mothers of babies in this group reported that obtaining a diagnosis was an extended chain of events complicated by conductive hearing loss, diverse professional opinion and appointment systems.

Mother A4/scr reported that follow-up appointments were slow to arrive because a professional view was that her baby had delayed physical milestones, which was contrary to her view that her child was progressing as she expected. More importantly, however, her insistence was not sufficient in this case to bring hearing tests forward. This mother’s professional relationship with an ENT enabled her to get an appointment to an outpatient’s clinic, a conductive hearing loss diagnosed and a myringotomy (grommet insertion) was organised. When this mother learnt that her baby was to have a general anaesthetic, she insisted that an ABR be undertaken simultaneously which resulted in the diagnosis of a severe to profound hearing loss. Retrospectively, she questioned a system that allowed her, a mother, to make this diagnostic call or demand this test as an option.

That [the ABR] was my choice. But you know in hindsight I think why did they let me make that choice? I think you know, they should have said, ‘well you know we have to do an ABR now’ like I don’t know why, now, they let the parent…. they [emphasis] should have pushed to have the ABR then, themselves. (A4/scr)

Whilst mother A4/scr understood the implication of a conductive hearing loss, and she did notice an improvement after surgery, she said that she knew intuitively that grommets were not the complete answer and they were “not everything her baby needed”.

Mother A5/scr also said that the ENT reassured her that when her baby’s middle ear problem was resolved, his condition would improve. In this case and in contrast with mother A4/scr’s story, this ENT routinely conducted an ABR during the surgery, which revealed an asymmetrical hearing loss. The surgeon inserted the grommets and informed the mother that the baby had a profound hearing loss in the left ear and a mild/moderate hearing loss in the right. This mother said that it “all started from there”. However, she was critical of the flow
of information to her during the preceding period, as she now understood her child’s deafness to be a degenerative loss of hearing. Despite many hearing tests and visits to Australian Hearing, she said she had relied mainly on medical information

…and I still don’t understand how you can have a child who is becoming profoundly deaf and not explain the whole thing to me. I found the ENT definitely the best one there. (A5/scr)

Mother A6/scr also received a referral to an ENT who diagnosed a conductive hearing loss and said surgery was required immediately to insert grommets. This mother said she was relieved as finally she had a doctor “that knows what he’s doing and he’s on the ball and he’s pushing to get things done really quickly”. Not unlike other concerned mothers, where conductive hearing loss was diagnosed and improvement was promised, her child did not improve after surgery. The mother reported that her child became increasingly frustrated and screamed continually. In desperation, she said she telephoned the ENT to say that her family situation had deteriorated to a point that

…..our house is like it’s on fire. We’re literally fighting with each other all the time and this poor little girl is screaming and frustrated all the time because she can’t understand me and I can’t understand her. (A6/scr)

Mother A6/scr reported all the evidence about her child’s auditory behaviour, including touching her to get her attention and always presenting everything in concrete and/or visual ways. The mother returned to the family doctor, and she recalled trying to demonstrate her child’s behaviour using a loud noisemaker toy to convince the doctor of the problem

I said [to the doctor] ‘well she puts that right next to her….squashes it nearly into her ear when she plays that. I didn’t know whether this meant that she could hear a tiny little bit of it or nothing at all. I just don’t know what’s going on but that would blow anyone’s eardrum out. She’s trying to hear. (A6/scr)

The doctor’s response was to make another referral where the mother was told that her child was too old for an ABR and some behavioural testing was
attempted. The mother recalled that as soon as the child saw the puppets she knew that the situation would be difficult. The mother referred to her daughter as “cluey” and “really smart” when she said that her child knew the game with the puppets but not how to play.

I don’t know whether she picked up on a certain body language once that the tester started or she’s ended up looking at the puppet or near to at the same time as the sound was there or it had just gone or whatever. Just too many times to just be a coincidence. I felt that she didn’t hear what she was meant to hear she just caught the puppet in time every now and then.             (A6/scr)

The mother reported that the audiologists thought hearing loss was likely, and they recommended further testing. Further testing conducted locally was ultimately abandoned for a second time, because of the child’s difficult behaviour; the paediatrician suggested that the mother should consider “intellectual disability” as a cause of the problem and the mother said she was upset when she saw the word autism written in her daughter’s notes.

The mother explained how personal judgments about her and her skills as a mother had framed the professional responses to her concern about her child in three ways. First, she believed that because she was a teenage mother, professionals were reluctant to tell her that her child was deaf. Rather she felt that professionals hoped the child would have something else wrong other than deafness. She qualified this statement in the following way:

Obviously it might not have been like that but I felt like that because how could they not have known that she’s not hearing properly when you know from everything I’ve read and I’ve seen and studied at school and everything like that she shows absolutely everything for a deaf child.             (A6/scr)

Secondly, she said that the professionals had not taken into account the evidence she had about her daughter’s behaviour.
I think if they had listened to me properly……if they had actually listened and took in what I said then things would have got done earlier. I sort of look back and think maybe the fact that I was a young Mum and up there and there are a lot of teenagers that are always pregnant and stuff that, they don’t always necessarily take on the responsibility as well as they should. I sort of find that possibly they just popped me into that sort of category you know she doesn’t know what she’s talking about or maybe she’s looking for a diagnosis to get more money or something like that… (A6/scr)

Thirdly, although she had recognised that child’s behaviour was difficult, she had arranged some speech therapy because she knew that her child was trying to communicate and she looked “talkative”. Indeed, assessments had documented progress. When the family moved interstate, this mother started again. She obtained a referral to audiology services and her child was diagnosed with a profound hearing loss at four years of age.

In summary, these qualitative data reveal that for these mothers with babies who passed the hearing screen at birth, it was more difficult to obtain a referral for a hearing test if a mother raised a concern at a later date even with evidence of poor speech and language development. In two cases, professional views of a child’s behaviour and developmental delay were unrelated to a potential for hearing loss.

4.11 Diagnosis

Quantitative data showed the respondents in both the UK (n=39) and Australian (n=53) cohorts recorded their child as being in the ‘severe/profound’ or ‘profound’ category of hearing loss. Six Australian respondents recorded their child’s hearing loss as moderate (n=2) or asymmetric (n=4).

4.11.1 Mothers’ understanding of audiological terms

The questionnaire asked respondents to say how they understood the terms used to describe hearing loss and a range of choices was offered. Respondents were able to select as many options as they liked to reflect how their child responded to sound.
In the UK 80% of respondents said their child could hear ‘loud sounds’ but not ‘voices’. The remainder of the respondents checked boxes that related to both ‘loud sounds’ and ‘some words’. One mother, additionally noted in the margin of her form, that it meant she needed to “shout words”. In Australia, 57% of respondents said that their child could not hear “their voice” and half of these respondents said that their child could hear “nothing”. Similar to respondents in the UK, the remainder of the Australian respondents variously recorded that their child’s hearing loss meant that they could hear ‘loud sounds’ or a combination of ‘some sounds’ and/or ‘some words’.

In the interviews mothers in all cohorts generally said they had little understanding of audiological terms associated with hearing loss at the time of diagnosis. Some audiologists attempted to put technical information into plain English, such as when mother UK2 heard the level of deafness was like “putting Concorde through his ears.” That the hearing loss was permanent was confronting as noted by this mother in the following extract.

Well I wasn’t happy with the way they worded it. They were very reasonably friendly throughout. But the way they worded it was ‘Baby’ has a permanent [emphasis] hearing loss as opposed to perhaps saying a profound hearing loss and then explaining that a bit better. When they said permanent I freaked out a bit not thinking there was anything they can do you know, permanent meaning you know that what’s he’s stuck with…and that’s the end of that. They used the wrong wording and I always look back at that and wish they hadn’t have said it that way.

(A1/scr)

4.11.2 Mothers’ responses to a diagnosis
The qualitative data revealed that for all the mothers the diagnosis of a permanent hearing loss was an unexpected event. Many of the mothers started their accounts by talking about expecting a baby as something long awaited and anticipated, or wanting to extend the size of their family. They discussed their pregnancies in terms of their own health, fitness or a capacity to carry on as normal. Three mothers from the UK compared the pregnancy with the deaf baby to other pregnancies. Two Australian mothers specifically reported no problems during pregnancy.
Four mothers in the UK stated that the delivery of the baby was normal, and five mothers in Australia mentioned their birth hospital and three of those mothers said that the delivery was normal. One mother from each group said that their babies were born quickly in the second stage of labour. One mother (UK4) reported her baby to have swallowed meconium, which required aspiration, whilst another mother (A3) said her baby required oxygen and was placed in a special care nursery for half an hour. Of the mothers who recalled their pregnancies or birth stories, none suggested that the particular experience was extraordinary. Generally, the experience fitted with their expectations about how they would feel and how mothers and new babies should be.

The diagnosis of hearing loss was a shock for all the mothers and they were unprepared for the severity and the permanence of their baby’s hearing loss. Even the mothers in the non-NHSP cohorts, who had displayed a keen sense early that something was wrong, reported their disbelief that the diagnosis was so definitive, final and irreversible. Mothers in the NHSP cohort similarly were also shocked and upset. Mother A2/scr was “upset and not very accepting of it”, whilst mother A3/scr said she was shocked because the deafness was “worse than anticipated”, A5/scr said the shock was because the family “had absolutely no idea about anything”.

For mothers who went alone to a hearing test that resulted in the diagnosis, being alone became a poignant part of the experience and is reflected in these quotations.

…and get in the car and drive home …I don’t know how I got home. No it’s not something that you should have to face on your own and had I been warned even slightly of the severity of it I would never have gone alone. (UK4)

…and they told me right away that she’d definitely got a problem, so I was absolutely devastated because I’d gone on my own. (UK5)

I guess it [seeing an ENT] was so soon after diagnosis that what I needed was my husband to be there and I felt alone. (A1)
Two mothers who went alone to the testing just wanted to leave the hospital and go home.

All I wanted to do was to get out of the hospital. I wasn’t staying there another minute. It was almost like it was their fault and as long as I was there I was being reminded of it. I had to get out. (UK2)

Well that day, I remember feeling that I just wanted to go home because the rooms were too small and I….. and all the people…. and I didn’t understand it and I had other things I should be doing. (A7)

Interestingly, all the mothers who went to test appointments alone held similar views about the unlikelihood of a hearing loss prior to testing; they had believed the tests to be routine. That permanent deafness was difficult to comprehend was representative of the comments from most mothers at the time of diagnosis.

I wasn’t really understanding what hearing, or loss of hearing is like. It’s so complicated. (UK5)

And he said or 80 [per cent] and I said ‘Oh, OK’, and we looked at each other and said, ‘that’s OK that’s not too bad.’ We thought he meant that’s what she could hear. And he said, No, that’s the loss.’ And when he said that to me it was a bit of a shock. I thought to myself ‘Oh my God that’s a major loss. (A3)

And when he told me that she was probably bi-laterally profoundly deaf. I had no idea. I had no idea what it meant (A7)

When the audiologist said to us that he has a profound hearing loss I’m thinking, ‘What does that mean?’ Just tears and all yeah…….yeah (A5)
I actually thought that was a description of what was wrong you know like ‘huge’ or….. that was just the term that she used I’d never heard it before I’d never…//..and the second audiologist stayed with us and when the other one was out of the room I said to the second one, ‘when she said profound hearing loss what did she actually mean?’ and that’s when she said, ‘well we grade hearing losses and so…’ It was interesting that as a professional looking at it I think the first audiologist did have a sense that we could have ‘not known’ exactly… but when do you introduce the terminology? (A4)

We just sort of waited with baited breath what the audiologist would say to us and I think in the end, her exact words were ‘it’s not as good as I hoped it would be. She’s profoundly deaf in both ears’ and we just went, ‘What? …What’s profoundly deaf? What’s going on?’ And I think you have one of those moments when time just stays still and you just don’t……… (A3/scr)

According to the accounts of mothers with babies managed by an ENT with regular medical reviews for OME and conductive hearing loss, the shock was no less intense. Mothers had a general understanding about grommets and their potential to fix a hearing problem.

So we went into that appointment thinking that she has fluid on her ears and this is what happens. When we…. they sat us down and they said she won't be able to hear even when they drain it (fluid) off so..... //Until that point I don't think we ever even thought that it was anything more than maybe she needed...because our friends had just had their kid having grommets that sounds just like what's happening to us 'our kid had tubes and it's fine it's such an easy procedure. (A11)

So most people didn’t know that we had any concerns at all, some people knew that we were having tubes put in but that was it. So all of a sudden it came up that he was deaf and sort of…What do you mean? (A4)

Mothers of babies without conductive hearing problems typically reported that they also had a sense that deafness could be fixed and some mothers also talked about grommets in this context. Mother UK2 talked about deafness as
something that would be “sorted” and she admitted that her understanding of deafness at the time of the diagnosis was as a blockage that could be fixed and she said she waited for an appointment for this to happen.

I didn’t think for one minute that it would be a problem that he would have it for the rest of his life/ Yes he’s deaf and yes he couldn’t hear, but I still had a bee in my bonnet that they would find that it was something that could be fixed. I was devastated. (UK2)

…and I didn’t even fathom that she would be deaf for life and what that actually meant. I just thought that at the back of my mind that she can have an operation and that she’d be fine. I just so didn’t get it. // I thought she’d be fine or there would be something they could do to fix it so when they asked me if I was OK and I said I was because I had no idea. It didn’t mean anything. (A7)

Well, for me really, I was really led down the path of grommets….that was the way I was thinking. (UK4)

Yes but that was just ignorance, just because you know a friend had just had grommets and it just hadn’t entered my head that she would be completely deaf, could hear anything…I thought grommets would fix it. (A1)

Yes, I think we thought that it [the deafness] could have been fixed. (A7)

Interview data revealed the initial impact of deafness on mothers was broadly determined by their understanding of the problem at the time of diagnosis. In the UK, mother UK1 said when the deafness was confirmed she thought that a profound hearing loss meant that her child would “never do this and never do that” and she said she preferred to be separated from her baby; she pushed him away because she “couldn’t stand it”.

I was looking at him. I was hating him…I look at him and have pretty awful thoughts, but I loved him so I was keep close to him but I looked at him I thought, this is miserable this is not what I was expecting…our lives just changed drastically overnight. (UK1)
Similarly mother UK4 said the profound deafness challenged her relationship with her baby to the extent that she felt she had gone in with a child she knew about and had come back with a “different child”. This mother described her response to deafness, as an extended period of uncertainty, stretching possibly for years. She said there were different phases although she described her responses as always emotional according to how things were going.

Corresponding qualitative data from Australia revealed that mothers’ initial responses were also determined by information received at diagnosis and how they broadly understood the future. In addition, when Australian mothers in the non-NHSP cohort looked back at how they raised their concerns, their perceptions were of time wasted. Mother A2 said that after six months of the “unknown”, she felt the diagnosis helped her to move forward because they knew that deafness was the problem and they needed to deal with that. Mother A1 said she was given a research paper after the test, so she learnt on the day that an early diagnosis was important. She viewed the future with a sense of panic about the time she had already wasted.

   Basically it was as you know plain as the nose on your face, the earlier you get it the better and I’m thinking wow, you know, we’ve lost a year. So it was the day she was diagnosed so I went into panic.  (A1)

Mother A1 also reported that she asked the audiologist, who diagnosed the hearing loss, what deafness would mean for her baby. Hearing a hopeful message about the future that the baby could learn to talk was important at the time.

   It was really good to hear that and it gave me some sort of… almost hope, suddenly sort of plummeted down and then I had the hope that we will work through this but there is a path that is forward…(A1)

Immediately after the diagnosis, the audiologist offered mother A1 an opportunity to talk to an ENT who happened to be free, which she accepted.
The ENT doctor who sort of happened to be free... I guess fairly perfunctorily sat down and said to me this is what you have to do and she gave me a list on a piece of paper of the things that we needed to go through and the early intervention centres and things and I.... She wrote it all down on a piece of paper for me on the back of an envelop, which was terrific because I really didn’t remember anything from the meeting I was still sort of you know very shocked. I’d only sort of known for about an hour and it was terrific that we went straight away to see the ENT and that was great for me because I just felt like I needed to do something straight away..... so she gave me the piece of paper.

(A1)

Talking to someone immediately after receiving the test results and having information worked well for this mother as she had waited a considerable time for the appointment because of the summer holidays; it was a good fit with this mother’s need to “go and do something”.

For mother A3, the diagnosing audiologist gave a pessimistic message about the baby’s future and learning to talk. The following week a second audiologist, who confirmed the earlier results, gave an optimistic message about the capacity of deaf children to learn to talk. In retrospect, the mother said that she was pleased that the appointments were close together so that she did not have time to dwell on the comments from the first audiologist. Even though she had never met a deaf person, her perception was that deaf people did not talk. For this mother, being positive about the future was important. Mothers A8, A1 and A4 confirmed this view. After the diagnosis, mother A8 said audiologists spent time with her talking about the future. Mother A4 said that the audiologist gave a clear message from the start that hearing aids were not going to benefit her son and their discussion about the future included cochlear implant surgery. This was important to this mother because it was encouraging.
She [the audiologist] said, ‘You may choose that your child undergoes a cochlear implant,’ and we said ‘What do you mean by choose?’ and she said that some parents choose not to have one for their child, and we then said what would that mean for ‘child’? That’s when she said that he wouldn’t be able to hear enough to speak. And that….. and it still makes me quite emotional…it had never really clicked that way if you get what I mean?// When you realise that at his level of deafness without the operation to get a cochlear implant he wouldn’t be able to talk. (A4)

Australian mothers in the NHSP cohort whose babies were diagnosed in the first few weeks of life echoed these sentiments. Mother A3/scr said that in the immediate time after the confirmation of hearing loss, all the right things were said to her. She described the experience as twofold. First, professional conversation focused on her baby and not the deafness, and second, she was helped to understand that her journey as a mother would be different from the one she had expected. Mother A2/scr heard similar positive professional messages in a meeting with professionals after diagnosis, which she described as “perfect”. These mothers said that important aspect in facing the future was that the hearing loss had been discovered early to enable timely hearing aid fitting.

It is noteworthy here, that all the mothers who mentioned feeling positive about the future spent time with professionals immediately after the diagnosis. Mother A4 said the audiologist had estimated the time it would take to test her child and set aside more time after that; she asked the mother not to make any appointments after the assessment which, retrospectively, A4 believed was a way of preparing her for the news of her son’s profound deafness. Only one mother (A7) reported that she felt very emotional and confused when she learnt of her child’s hearing loss and refused any further discussion. Sensing this, the audiologist made all the necessary referral appointments and arrangements on her behalf. Looking back, she knew this was the correct approach for her.

In summary, the diagnosis of a permanent hearing loss was an unexpected event for the mothers in both the non-NHSP or NHSP cohorts for which they were unprepared. Irrespective of the presence of OME, most mothers believed
deafness to be fixable. Positive messages about the future appeared to relate firstly, to the extent to which professionals were sensitive to the mothers’ needs immediately following diagnosis, secondly, to the time they took to explain the results in a personal way, and thirdly, the informative they gave explaining their child’s potential progress.

### 4.12 After diagnosis

Respondents to the questionnaire were asked to say what they did following the diagnosis of their child’s hearing loss and this is shown in Appendix E. The question was open-ended with space available for written comments. In the UK cohort, all the mothers answered this question with at least one statement. In the Australian cohort, 48 mothers made responses to this question and 30 (57%) respondents made more than one statement. These data reveal responses that could be categorised in two ways, 1) feelings, and 2) actions. The interview data enriched the definition of these two emergent categories.

#### 4.12.1 Mothers’ feelings

In the UK (n=37) “crying” or “getting angry” accounted for four (10%) mothers’ responses. In Australia, three (6.2%) mothers recorded emotional statements only, and these related to being ”shocked”, “crying for a year” or feeling “isolated, no facilities where the child was born”.

Mothers’ accounts provided deeper insight into their feelings and responses to the diagnosis. Statements such as “I was in depression for a whole year after that”, “we had a lot of crying nights” and “I just felt that I had this no-hoper in my arms” exemplified the deep shock experienced by mothers. Three mothers (A2, A6, and UK6) expressed feelings of relief and others blamed themselves. Mother UK1 looked for someone to blame and she took her baby back to her home country to see a healer.

> We looked to blame each other and whose fault it was or I didn’t eat the right thing. Before I used to say he’s got an…hearing problem, until I was able to say he was deaf I was not coping very well at all.

(UK1)

Mother A8 said that she should have been worried and felt sorry that she missed obvious signs of a problem. Mother A11 said:
Well a whole year?..... it’s a really long period of time to not notice something like that. We thought well if she really is that deaf why would we have not noticed that you know? // We felt lousy parents. We have another daughter now who is not deaf and it’s obvious.

A11

Mother A2/scr likened how she felt in those early stages as being “in a cave” where it was very hard to get out into the community or even tell her friends.

I even went to a mothers group and I just didn’t tell anyone at the group because I’d told the nurse [about the deafness] I said I just didn’t want her to tell anyone and I just didn’t want to talk about it. I just hadn’t accepted it yet I didn’t know then but I was quite depressed…..Yes going out in public I avoided every one, even someone I knew I avoided them. I had my baby in the pram and I know we caught each other’s eye and I turned away with the pram and walked in the other direction. I realise now what that was about, what happened then.// I didn’t perceive him differently I just thought that others know he was deaf and at that stage deaf was a bad thing.

A2/scr

For mother A4/scr, being a professional in the field was central to her distress.

I was just upset for ‘Child’ and all that time wasted and what he had been through. I felt very guilty that as a professional, I had not listened to my gut feelings...my instincts and been more assertive. I was disappointed with the hospital conduct – they totally mucked up and I must say ‘Child’ fooled them all.

A4/scr

4.12.2 Mothers’ actions

After diagnosis, analysis of quantitative data revealed that respondents in both cohorts talked to and/or contacted others. Respondents’ written comments were clustered according to what they said they did next, which emerged as themes, providing the context for their action (see Appendix C1). In general, the responses from the UK and Australian respondents were not comparable and are reported separately.
4.12.2.1 Mothers in the UK

Ten mothers (28.2%) recorded a response that included a medical professional e.g. talking to a health visitor or family doctor or seeking a referral to an ENT. None of the mothers who indicated a medical professional wrote statements referring to education or education department professionals. Fifteen (38.4%) mothers made statements about “teachers”, “deaf schools” or telephoning the “education department”; four mothers referred to “school holidays”. Of all the statements written, 41% of mothers referred to education in some form.

Seven mothers said they waited; waiting referred to ‘waiting for teachers’ in three cases and ‘waiting for hearing aids’ in four cases. This type of ‘waiting’ accounted for the mother’s action in 28.2% of cases. Six mothers in the UK said they did “nothing” or “not much”. These data reveal that four mothers who wrote that they waited because it was the school holidays were not the same seven mothers who said that they waited for a teacher or hearing aids.

Of the mothers who were specific in identifying what they did next, gathering information accounted for mothers’ actions in seven cases, six mothers said they rang up either The Royal National Institute of the Deaf or The National Deaf Children’s Society or “visited” a deaf school. One mother said she asked a friend. Analysis of these data suggests that mothers in the UK had an expectation that someone would visit the home, which corroborated the mothers’ interview data where home visits started automatically as a result of the diagnosis and/or the mothers waited for this to happen.

Table 4.7 Emergent themes from questionnaire data asking what mothers did next

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<td>Hearing aids/fitting/ Australian Hearing</td>
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<td>Nothing</td>
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Chapter Four: Results
4.12.2.2 Mothers in Australia

Analysis of the questionnaire data revealed that 87.5% of Australian respondents “went”, “were referred”, “were directed” or “were sent” somewhere, which suggested a next stage or steps in a process. Mothers’ actions in Australia were broadly categorised as those involving hearing aids, information, medical appointments or early intervention programmes.

More than 50% of respondents mentioned Australian Hearing and/or hearing aids in their written statements. Apart from hearing aids and their fitting, 35.4% of respondents said that the next event was medical. Seven (14.2%) respondents consulted an ENT, three respondents (6%) sought a second opinion, and in nine cases (18%), respondents said that they went to a cochlear implant clinic or searched for information about cochlear implants. One respondent stated only that she was “looking at therapy options” and another said “medical people told her where to go”.

Over 33% of respondents wrote about early intervention programmes, and various contexts were identified. These were: to research and/or consider the options, to contact and/or enrol, or alternatively, respondents said service providers contacted them at home. Analysis of these data according to non-NHSP and NHSP cohorts revealed that 39.2% of mothers in the non-NHSP group contacted, enrolled or visited an early intervention programme, whilst 20% of mothers in the NHSP group said they contacted a programme. Only one mother in this group said she enrolled.

Analysis of the Australian questionnaire data revealed that 95.7% of mothers went somewhere, either for a next appointment or to find information. Information based steps accounted for 25% of mother’s responses, which included “telephoning”, “considering options” or making “choices or decisions”. Aside from these events, 10% of respondents also noted they had either “lots of appointments” or “lots of tests”. In contrast with mothers from the UK, only three Australian mothers (6%) used the word “wait”, and this was specifically in the context of waiting for appointments.
4.13 **How mothers found information**

The questionnaire asked where respondents found information following diagnosis and the interview data strongly suggested that mothers wanted information at this time. In the UK, first encounters with a professional were with a teacher of the deaf who automatically visited the home. These teachers provided information and shaped how mothers begin to understand the deafness problem and the mothers’ accounts from the UK are not comparable with those from Australia so the analysis is therefore presented separately.

4.13.1 **Mothers in the UK**

The quantitative data support qualitative data which revealed that mothers did not have to make a choice about a first specialist professional as all the respondents recorded that a home based intervention programme was provided to them from the Local Education Authority by a teacher of the deaf. This started within a week of diagnosis except when it was school holidays. Three mothers wrote in the margin of their questionnaires that they could not remember if the person who told them about the services for hearing impaired children at the time of diagnosis was the same person who first visited their house.

For mother UK1, beginning to understand about deafness started with the visits from the peripatetic teacher of the deaf, although she said that she had no memory of how this professional arrived at her house. Until the visits started, she said that she understood the problem only to be something wrong with her baby’s ears; she added that she had little understanding about degrees of hearing loss.

> I think it’s not the health visitor, I think the hospital actually got her involved. I’m not really a hundred per cent sure how she came on to the scene…no, I can’t remember what actually happened she just appeared one day.  

*(UK1)*

Mother UK6 said she received a visit from a head of the peripatetic teaching service from the Local Education Authority as a result of a first set of hearing test results which suggested that her baby had a moderate hearing loss. After this visit, for a period of time, no other professional visited the house because
this mother was busy with a new baby and it was the summer school holidays. At the start of the next school term, the teacher of the deaf encouraged this mother to seek further audiologic testing, and a second diagnosis was made of a profound hearing loss. At this point, the mother reported that she made the decision to get on with the job and do the best she could.

I looked at ‘child’ one day and thought well, she’s still the same person, she doesn’t know any different, so we’ve got to get on, there’s no point in sitting back, you’ve got to give her the best you can.

(UK6)

Mother UK4 reported the first few weeks following diagnosis as a blur. There was so much going on particularly with professional people at the hospital who, she said, all knew so much more about her child than she did. She said that even though her family life was busy with two pre-school children to care for nothing further happened after the diagnosis, as it was the summer school holidays and no one visited the family from the education department. This mother recalled the period of time immediately following diagnosis as distressing and a “gap”.

I can remember that [the deafness] being quite a struggle. // You need to know what to do…how to cope with it. You need to speak to people about it. I needed something to get on with.

(UK4)

Mother UK5 said that a teacher of the deaf visited her house soon after her baby failed the first HVDT but before a referral to a hospital for further assessment and the fitting of hearing aids. The mother reported that it was another seven months before a hearing loss was confirmed and her child received her hearing aids. She said the purpose of the visits seemed to be to show her about hearing aids and talk about communication options in the future.

Mother UK2 struggled with the diagnosis of permanent profound hearing loss and the initial visits to her house by a teacher of the deaf. The mother’s view of the problem was that deafness was something that could be fixed. The alternative professional perspective that saw her baby as “a very disabled child, who was not going to have any life or be able to do anything and wouldn’t be able to talk” was overwhelming. During the interview, the mother became
agitated. She talked in the present tense as if it were happening all over again and she said:

I was told I should be signing with him, I don’t want to know anything about signing, I don’t want to sign, whoa whoa [refers to self] I’m putting my foot down for two seconds….He is not [emphasis] signing. (UK2)

Her way of dealing with this was to slow down the flow of information and she blocked any further contact with visiting professionals from the education department.

In summary, mothers in the UK received visits from teachers of the deaf from the Local Education Authority, which started soon after diagnosis. For mothers with babies diagnosed in the school holidays there was no service.

4.13.2 Mothers in Australia
Quantitative results showed that the primary sources of information for mothers were hospital audiologists (Aud), audiologists from Australian Hearing, or ear nose and throat specialists (ENT). Respondents were able to check more than one box and 35.4% said that they received information from more than one source following diagnosis. Of the 50% of respondents who selected a hospital audiologist, a further 50% selected a combination of sources of information that included an Australian Hearing audiologist and an ENT. When an audiologist was not the main source respondents selected a single professional, which included, ‘Education Department’ (4 cases); ‘friends’ (2 cases); ‘Internet’ (2 cases) and ‘other’ (5 cases). In the NHSP cohort, quantitative data revealed that 50% of respondents received information from a combination of sources. More than 50% of those respondents checked that they received information from an audiologist from Australian Hearing. A further 66% also checked a hospital audiologist or ENT as an information source. Similar to the non-NHSP cohort, these data revealed other sources that did not include an audiologist. These were ‘The Education Department’ (2 cases); ‘friends’ (3 cases) and ‘other’ (4 cases). Four parents wrote on their questionnaires that they were ‘in the field’, which implied that they did not need information as they knew what to do. These
included two speech pathologists, one auditory-verbal therapist and a mother
with a husband employed by a company who made cochlear implants.

For some mothers interviewed in the non-NHSP group, making up for lost time
was a common theme that characterised how they looked for information. These
mothers wanted to find information quickly as a way of redressing the delay.

Mmmmm I guess I just wanted to do things so fast because I was so
worried about the fact that I’d left it so long that I felt guilty. (A1)

Mother A5 said that with an earlier acknowledgement of her concern, she felt
things would have been different. She talked about not knowing about the future
as information flowed to her in “bits and pieces” which were neither specific to
her nor her baby. She had a clear view about what she wanted and said that
someone needed to explain deafness to mothers as the brochures she received at
the time of diagnosis were not enough for her or her family. Mother A6 said she
felt sorry that she had known so little about permanent deafness as she felt like
she had "betrayed" her baby. When she came home after the diagnosis, she said
that she confronted what deafness meant by searching on the Internet alone as
she saw little point in waiting to have it explained to her because she wanted to
get on with it.

It was all through the Internet. I didn’t talk to anybody. When she was
diagnosed at the ‘hospital’ and when we came home we read through
that book and there was quite valuable information in that so I just
went on the Internet and I probably spent …..I reckon 48 hours without
sleep just resourcing all the various schools basically…. (A6)

Mother A11 said that she wanted to “hide”, although she explained hide in
terms of not particularly wanting to go out to different consulting rooms or
offices to hear general information about deafness. She wanted someone to
come and explain it to her with respect to her own child’s deafness, which
resonates with what mother A5 said. Mother A11 said that her needs for
information were met when, as a result of the diagnosis, she received a
telephone call from a counsellor from the Education Department who made an
appointment to visit her house and inform her of her options.
It was good because we knew at that point that we had a lot of options, overwhelming because you know you only just find out that this thing is just going to change your life... and you find that there is all that information out there, but I don't think she could have done it any other way. So I think that that was handled really really well, very professionally. Yes it was a whole pile of information and really overwhelming and my husband couldn't be here at that appointment he had something on with work and so it was a lot then I had to pass on to him but how she did it and how they went about doing it was really good. (A11)

The mother reported positively about the meeting but regretted that it was a single session and her husband was unavailable. She said that she was disappointed that there was not a second chance to speak with the counsellor further, because hearing aid fitting raised other questions and aroused different emotions. This mother clearly expressed her need for a follow-up appointment of this type because she wanted someone who knew her and did not like repeating her story time and time again.

After the diagnosis, mother A2’s sense of relief was replaced by frustration that it had taken her so long to discover the cause of her baby’s problem. Delay for her meant that she had not used strategies that were best suited to developing her baby’s communication skills and she blamed herself for this.

We didn’t know how to treat a child with anything wrong with them so we just treated her like any other child and that was normal and that wasn’t the right way and she wasn’t developing and she wasn’t growing and she just wasn’t interested in anything. She had no communication… (A2)

Using the right approach in a context of understanding the extent of the problem became an important factor also for mother A10. Until the time she contacted a ‘city’ specialist centre for hearing impaired children, she said that she had received insufficient information from hearing aid fitting and audiological reviews that addressed the whole deafness problem for her son. Enrolling in a specialist centre meant that his deafness became central to planning an approach for the next stage; new information from a different source clarified many issues.
for her. Even though she described the next few months as a roller-coaster ride because things moved so quickly, she said that in retrospect, she would have preferred to have the full picture of the deafness problem at the start.

Mother A12 said that the information given to her by the private audiologist who diagnosed her child, explained clearly the two avenues of approach in each of the next stages. First, she had information about a cochlear implant and a referral to a cochlear implant clinic and second, she had information about early intervention programmes and an understanding of communication options associated with each programme choice.

The three mothers in the Australian NHSP group, whose babies were diagnosed at birth, typically said they received appropriate information at the time, however two mothers, A1/scr and A2/scr, said that when the referrals for services were slow, having only general information about hearing loss given at the time of diagnosis was not enough. Mother A2/scr also commented that she “just wanted everything to happen tomorrow”. It was not enough simply to know “what to do next” yet this was all the preliminary information she had.

In summary, five Australian mothers in the non-NHSP cohort regretted the delay in diagnosis, which shaped how they searched for and wanted their information to be given. Audiologists and ENTs were the professionals most likely to give early information to mothers. Information for mothers in the NHSP cohort was appropriate to start with but delays in referrals resulted in mothers wanting more support while they waited. Early positive messages were important for all the mothers although they wanted information that was personal and suited their individual needs.

4.14 The unfolding of intervention

Following a diagnosis, intervention and the management of hearing loss meant that mothers needed specialist services, such as further audioligic assessment and hearing aid provision, early childhood intervention programmes or other medical appointments, e.g. genetic counselling. The process for the mothers was different in each country. In the UK, hearing aids were fitted and managed by hospitals and education services together and mothers’ relationships with service providers reflected only those systems. In Australia, the ways in which
mothers accessed specialist services was complex. All newly diagnosed deaf children were referred to Australian Hearing, a federally funded organisation, which fitted, reviewed and serviced the hearing aids. Following diagnosis, some mothers were referred simultaneously to a cochlear implant clinic, making it difficult to analyse exactly how the timing and provision of each service unfolded in the broad process of mothers’ engagement with services.

4.14.1 Hearing aid fitting and hearing aid wearing

The questionnaire data revealed that in the UK, hearing aids were prescribed and fitted to all the children diagnosed in this cohort within three weeks. In Australia, 70% (n=37) of all children diagnosed in either of the non-NHSP or NHSP cohorts waited for four weeks or more. Figure 4.10 shows the time between diagnosis and the fitting of hearing aids in the total cohort of UK and Australian children.

![Figure 4.10 The distribution of the time taken between diagnosis and hearing aid fitting in the whole cohort.](chart.png)

Respondents were asked to indicate how long their child wore their hearing aids each day after they were fitted. Selections could be made from blocks of time...
during a day. These were, ‘all day’, half a day’ ‘less than 2 hours’ or ‘not at all’. The distribution for hearing aid wearing in both non-NHSP and NHSP cohorts is shown in Figure 4.11.

![Figure 4.11 The distribution of daily hearing aid wearing behaviour of children following diagnosis](image)

Results from the UK and Australian non-NHSP cohorts were combined (n=70). In the non-NHSP cohort, 14.2% of mothers reported that their babies never wore their hearing aids. No mothers in the NHSP group recorded non-usage. More than 75% of babies in the NHSP cohort (n=22) wore their hearing aids for half a day or more compared with 60% of babies (n=17) diagnosed by other non-NHSP methods. In the category ‘less than two hours per day’, 23% of babies (n=5) in the NHSP group and 40% of babies (n=28) in the non-NHSP groups were reported to be in this group.
4.14.2 Mothers’ responses to hearing aids

Respondents were asked to select responses that best described how they felt when their child was fitted with hearing aids; any number of boxes could be selected.

In the UK overall, 46.6% (n=35) of mothers indicated they were positive about hearing aids after diagnosis and 62.9% (n=22) mothers checked a box that said they were disappointed their child still could not hear them with a hearing aid. Twenty-two percent (n=8) of mothers said they disliked the look of the hearing aids and of those mothers, a further 17% (n=6) also said they disliked inserting them.

Interview data revealed that mothers in the UK relied solely on hearing aids as a listening device for their child. Two mothers again expressed a negative view about how hearing aids looked on their child. An interesting finding was that Mother UK1 reported that she did not allow her child to wear hearing aids outside the house because she feared being an “outcast” and found other mothers' questions too difficult. She was overwhelmed by the fact that her child could hear nothing and yet she was told to “put these things in”, referring to hearing aids. She said that she saw little connection between a hearing aid and her child’s needs, as hearing aids were for old people. Two mothers mentioned a “Phonic Ear” one of whom said that it attracted public attention. Similarly, mother UK2 was overwhelmed by standard responses and negative messages from professionals, which seemed to be, “just get them [the hearing aids]” and start the visits”. Mother UK6 said that she remembered impressions for molds being taken after the hearing test and it was at the second appointment that she was told to “try these”, which referred to hearing aids that seemed like “magic things”.

In Australia, 61.3% (n=19) of mothers in the non-NHSP cohort and 52.3% (n=11) in the NHSP cohort said they felt positive about hearing aids. Overall in Australia, 20% (n=20) of mothers stated they were disappointed that their children still could not hear them with their hearing aids and this accounted for 29% (n=9) and 52.4% (n=11) of mothers in both non-NHSP and NHSP cohorts respectively. In the total Australian cohort, 7% (n=4) of the mothers who said
they did not like the look of hearing aids, three also said that they disliked inserting them into their child’s ears.

The Australian interview data revealed that in contrast with mothers in the UK, hearing aid fitting and wearing was only a small part of a next stage of intervention and professional contacts. Moreover, mothers’ experiences of hearing aid fitting or their child wearing a hearing aid was influenced by their perceptions of the benefits of hearing aids. These data possibly indicate that mothers understood the serious impact of profound hearing loss from the beginning and audiologic information concerning the child’s age and the degree of hearing loss was taken into account and persuaded mothers to explore an alternative listening device. As a consequence, four mothers (A4; A8; A9; A10) went directly to a cochlear implant clinic.

I think once the information started to come in I think we sorted it out quite quickly, we were still very emotional, as a couple and as a family. We very quickly made that decision that we wanted ‘Child’ to go ahead and have a cochlear implant if he was eligible and that this first implant was going to give him access to sound and we both agreed fully on that and the quicker the better. (A4)

Mother A2 highlighted how audiological information made being positive about hearing aids difficult. Specifically, she said that at the start, precise details about the degree of hearing loss and professional disagreement about these levels, affected her view of hearing aids and their perceived benefits.

In the NHSP cohort, three mothers with newborn babies diagnosed in the first few weeks of life were referred to a cochlear implant clinic. However, for mother A2/scr, a key message from professional conversations, at the time of diagnosis, was to “get those hearing aids onto his ears”. In response to this message, she was anxious to get this process going quickly and she reported that having to wait for an appointment with Australian Hearing particularly stressful. Waiting for Australian Hearing was also how mother A1/scr remembered the next step after the diagnosis and could not understand why the process of referral for hearing aids took so long after such an early diagnosis.
4.14.3 Mothers’ observations of their child's responses to hearing aids

Respondents were encouraged to write down their observations of changes in their child when he or she started to wear hearing aids. These statements are shown in Appendix F. All the respondents provided qualitative information here except for one in the UK (n=38) and five in Australia (n=48). In the UK cohort, 15 mothers (39%) wrote single statements and in the Australian NHSP cohort, 11 mothers (55%) also expressed only one idea. Five mothers (16%) in the Australian non-NHSP wrote single statements whilst 23 mothers (82.1%) recorded more than two qualitative statements.

As a whole, the statements were personal and diverse. Some mothers recorded their observations of a child’s response to environmental sounds or speech, whilst others also included information about their child’s social demeanour, changes in behaviour or made particular comments about the hearing aids. The responses were coded into four different types of statements. 1) an observed response to sound, 2) changes in behaviour, 3) vocalisations e.g. babbling or speech, 4) hearing aids. Categories one and two were further coded into no auditory response/observed auditory response and positive/negative changes in behaviour respectively. Only six negative statements were recorded overall for all the mothers. A further category ‘other’ contained seven statements, e.g. “overwhelmed due to late diagnosis” or “looked cute”.

In the UK, 61 comments were recorded overall and 22 mothers (58%) said there was no change when their child started to wear hearing aids. Seventeen positive statements were recorded about changes in behaviour of which seven (18.4%) referred to an observation of a child’s response to sound. Many of the statements were directed towards hearing aids specifically and 19 statements recorded a negative view of the hearing aids or a change in their child’s behaviour with the hearing aids. Two mothers who made positive comments about their child’s response to sound also made negative comments about hearing aids and these were, 1) “he only liked his hearing aids for a while”, and 2) “she doesn’t like me putting them in”.

In Australia, in the non-NHSP group, 15 mothers (53%) said their child responded to sound whilst 8 mothers (28%) said their child did not. Positive
comments about changes in behaviour could not be classified specifically as auditory responses. For example these were: “appeared to enjoy music”, “more mature”, “more alert or “less clingy/more confident”. Of seven mothers who did not observe their child responding to sound, five mothers made negative comments about the hearing aids specifically. In the NHSP cohort, 14 mothers (70%) said they noticed no changes in their children with only three mothers (15%) recording a specific auditory response. Fewer positive statements (3) were written e.g. “quieter, stopped squealing” or “more responsive”.

Mothers who observed little or no changes with their children’s behaviour following hearing aid fitting were more likely to make other comments about hearing aids, e.g. “no benefit from hearing aids”, “hearing aids no use”, “hearing aids difficult to fit” or “feedback a problem”. Similar to the UK mothers, two mothers in Australia made seemingly contradictory comments. Whilst they made positive statements about their child’s responses to sound, they also commented negatively about hearing aids and they said that 1) their child “pulled the hearing aids out all the time”, and 2) “loud noises scared him”.

Analysis of the interview data from the UK revealed that early hearing aid wearing was both a difficult and confronting time for mothers. Mothers described managing their child’s hearing aids wearing in ways that were linked to the start of home visits from a visiting teacher. Three mothers said that their children were happy to wear their hearing aids after a while, although the mothers observed no responses. Mother UK1 said if she had known about the importance of maximising residual hearing, then her view of how her child wore his hearing aid would have been different. However, she only learnt this at the cochlear implant clinic much later. Mother UK6 said hearing aids made no difference and her visiting teacher told her they were not “powerful” enough and she was encouraged to seek a second opinion. Travelling to another region, her child was fitted with a Phonic Ear, yet the molds needed to be obtained locally. The costs associated with taking special impressions for the molds required by the device, attracted disapproving comments from local service providers who were reluctant to provide replacements at the rate required by the child. This type of cross regional arrangement was problematic and the mother reported that it was stressful.
For Mother UK2, the fitting of hearing aids and the start of home visits reminded her of how bad things were. Her child refused to wear the hearing aids and the mother blocked any contact with a visiting professional. Mother UK5 said she made sure that her child wore her hearing aids during all her waking hours and was disappointed when her child did not develop speech quickly.

For Australian mothers, hearing aid wearing and the professional expectation that they report a child’s responses were difficult when little or no response was evident. Mother A8 said that when it became clear that hearing aids seemed to be of little benefit, then only one option remained. This was to have a cochlear implant, although the surgery made this decision “scary”. For mother A6, not knowing what to expect from hearing aids was confusing, especially when the audiologic information suggested that they would be of little use. Mother A6 said that not having a real understanding of cochlear implants further complicated her views about any potential benefits of hearing aids.

….because she had a profound loss and no hearing and she didn’t get anything from the hearing aids, I wasn’t familiar with cochlear implants and what they would bring to her in terms of hearing and so forth….so….// I had heard the old term bionic ear, I think most people would know what a cochlear implant was by the old definition of bionic ear, so I’d heard of it, didn’t know what it looked like, didn’t know what quality of sound it brought to a deaf person I knew that they were better than hearing aids for a profound hearing loss, I was probably more…we were sitting there hoping that hearing aids would be able to give her enough to be able……to talk…. (A6)

Mother A9 confirmed beginning hearing aid wearing as a confusing time. Whilst her child’s responses with hearing aids were disappointing, his progress with speech therapy was encouraging. She believed that Australian Hearing was not aggressive enough with the monitoring and fine-tuning of the hearing aids in the early weeks, although she was reluctant to press for more urgent intervention.

When you’re in the middle of it all you don’t know how much to push the boundaries at all because you’re just the parent. (A9)
Mother A2 observed that hearing aids made her baby angry and aggressive and represented a change from the indifferent, unresponsive and passive child she knew. The mother understood the plan for her daughter to be, first, to trial hearing aids and second, if no responses were observed then a cochlear implant would be considered. Later, mother A2 received the news that implant surgery was not possible.

We were pushing it [hearing aids] because we wanted her to hear and they weren’t doing any good and we know that now but obviously at the time you do what we can and you think you’re doing the right thing for her. It did help her come out of her shell a little bit and then when we were told that the hearing aids weren’t doing any good and we can’t implant her and we can’t give her a cochlear implant and that was a real shock because we were really hoping for the implant. (A2)

Not all the deaf children in Australia wore hearing aids, because of their ages, profound deafness and direct referral to a cochlear implant clinic. This is in sharp contrast with all the mothers in the UK where mothers reported their child’s responses to the peripatetic teacher. In Australia, where children wore hearing aids, mothers were more often engaged with both Australian Hearing and a pre-assessment team at a cochlear implant clinic and they needed to engage with both groups.

### 4.15 Specialist Early Intervention Programmes

In the UK, mothers’ accounts of managing hearing aids and responding to their child’s permanent hearing loss, included reference to a peripatetic teacher of the deaf, from their Local Education Authority who visited their home and with whom they developed a relationship. None of the mothers called the visits from the teacher of the deaf ‘early intervention’. In Australia, some mothers talked about an early intervention programme although not all the mothers said they enrolled in a programme. The qualitative data results are not comparable and are reported separately.

#### 4.15.1 Mothers in the UK

Mothers in the UK received regular visits from teachers of the deaf from the Local Education Authority who were, as previously reported, a mother’s first
professional contact after diagnosis and their primary source of information and support. According to the mothers’ accounts the context for the visits appeared to focus on hearing aid wearing, communication and language development. As mothers adjusted to having a deaf child, relationships with the visiting teachers were variable. One mother (UK2), who prevented the visits at first, said it was because they reminded her of how bad things were and there was nothing anyone could do. Her baby also had asthma and was frequently hospitalised. On one occasion, when she returned from the hospital, a different person from the Local Education Authority service was waiting for her. She reported that she felt an instant rapport with this teacher and invited her inside, which resulted in a new relationship. She admitted that her reluctance to have a teacher come to her house was based on a belief that in some way the focus would be to do things differently; she did not want a “social worker” or anyone to use that type of approach with her to change her. She admitted also, that her reluctance to have a teacher come to her house was because she believed that every child was different and she failed to see how a teacher could help.

I couldn’t get my head around…. ‘teacher’. Maybe they’ve been given the wrong name. Maybe they should not be called teachers, I know they are teachers and to do this job you actually have to be a teacher. So maybe the word teacher is wrong you think the word teacher you think five years and upwards you don’t expect teachers to be coming to your house and teaching you how to bring up your child. The advisory bit — yes An ‘advisor’ — yes. You have to learn all about it first and at the time I didn’t take in what they said. What I don’t like is being pushed into something that I’m not happy about and this was signing…… (UK2

However, this teacher worked in a different way. The mother said that she felt included and indirectly supported and she did not feel that she was the target. The mother summed up the situation commenting that everything was changing; so it became that everything was “in my own time, she didn’t push me”.

Mother UK5 said she devoted all her time to her child and she approached her child’s profound deafness one day at a time because there was so much unknown about the future.
Life? It is hard because you feel pressures on yourself, all that responsibility is there, if you don’t help and support she won’t be able to achieve so much and you don’t know the targets are achievable and what she will be like. (UK5)

Intervention for her was weekly visits that included a deaf person who signed. She said that signing was difficult for her and the experience of the joint visits and different perspectives was very confronting and confusing and referred to herself as being “just like a child”. Alternatively, mother UK5 welcomed the weekly visits from a teacher of the deaf and her relationship with the teacher was friendly and “chatty” and she felt comfortable about asking questions. She liked the way the teacher included the older sibling as a way of explaining how speech and language develop.

Mother UK1 stated that from the start of the teacher’s visits she held the view that there was a long-term commitment to work together and the family felt able to make up their own minds about important issues with the teacher to help.

Mother UK6 enjoyed the support of a visiting teacher before a final diagnosis of profound hearing loss was confirmed. The teacher, who visited weekly, gave tips about the ‘Phonic Ear’ and types of useful listening games that the mother found useful. The mother reported that the teacher had been upset about an initial mis-diagnosis of the level of hearing impairment from the local hospital and it was she that encouraged a second opinion. She said the teacher worked hard with her child to develop her language commenting that she would not have liked to be without her.

Mother UK 4 said that at first she experienced a definite sense of loss for the child she thought she had and that she felt the pressure during the first few months. That her child was happy made the situation bearable. This mother also said that she felt like a child, which endorsed the view expressed by mother UK5. Mother UK4 made similar comment to mother UK2, when she said intervention strategies were difficult to practice, all the time knowing them to be underpinned by negative messages about the extent of her child’s deafness and that there was nothing anyone could do.
Basically you feel almost childlike yourself, because you don’t know anything about deafness so you are totally reliant on whoever walks in through that door who knows something about it, so you are guided. //You feel really inadequate, unable to cope I did, I felt very unsure of what I was doing. (UK4)

...basically what they were saying was, there is something wrong with your child, but ‘no’ there is nothing we can do about it….that’s how it felt to me. //You know basically that the hearing aids were never in a million years going to give her the output she needed, so everything went over the top of her head you know? I think initially I was like a sponge, doing everything she said to do ….and then I got my doubts really.// And I went through a long period of saying why is she [teacher] doing this? (UK4)

For this mother the intervention was confusing. On the one hand, her child was not responding and this was to be expected, whilst on the other, she was being asked to do more. She felt to blame for her child’s lack of progress. Overall, her view was that her baby had “switched off” and finally, she said, “they [teacher] couldn’t hold her concentration” and for a second time, she said she felt like a child, just wanting to switch off.

I remember feeling at the time that all I wanted to do was be a child and you know, do something else and take no notice of the teacher of the deaf. I felt anxious and this was a very important time and that she [the baby] shouldn’t waste it. This woman knows what she’s doing and if I don’t so make the most of the time she’s here.//……I felt totally useless. (UK4)

At this point, it became difficult for the mother to continue with the interview and the father entered the room to support his wife. The mother said that it was difficult when one point of view was that there was no time to waste; yet doing your best was not good enough. The father agreed; he felt that his child was very young to be subjected to this pressure.
You assume that they know what they are doing and they are telling you that you have to get in early so you go along with it, because you want to do the best for your child, so if they say that’s what needs to happen then you don’t say “No!” we’re not doing it” because you want to do the best thing. But do they? You have to assume that they know, they’re taught…with all their training…and stuff. // If you don’t feel you know the best, then you’re guided by those who you do feel do ‘know what’s best’ Father (UK4)

What eventually became clear to the mother, when there were no responses from hearing aids, no progress with teaching and an overwhelming feeling of despondency was that maybe this method was not “the right way”. The relationship with the visiting teacher broke down and the mother’s perception was that the service was the same for everyone irrespective of how you were feeling.

You’re grieving….. they [professionals] don’t grieve. They don’t give a hooey (UK4)

In summary, specialist intervention in the UK was a home based continuous service from the time of diagnosis. The data reveal mothers’ experiences of the visits varied according to the progress of their children, their use of hearing aids and their expectations for the future. Some parents reported pressure to achieve goals or adopt different approaches whilst others reported a sensitive relationship, which embraced mothers’ perspectives.
4.15.2 Mothers in Australia

Figure 4.12 illustrates the timing of mothers’ entry into a specialist early intervention programme.

![Bar chart showing entry into early intervention programmes following diagnosis in total Australian cohort](chart)

**Figure 4.12 Entry into early intervention programmes following diagnosis in total Australian cohort**

This Australian data as they relate to mothers enrolling into a specialist early intervention programmes need to be considered from a perspective of mothers’ choices. The quantitative data suggest that some mothers waited before starting an early intervention programme. In the non-NHS cohort, 75% (26) of mothers enrolled in a programme within four weeks compared to less than 20% (6) of mothers in the NHSP cohort. In the NHSP cohort, 54% (12) of mothers enrolled in an early intervention programme between two and six months after diagnosis compared with 16% (5) of mothers in the non-NHSP cohort. Of mothers enrolling in an early intervention programme later than six months after diagnosis 18% (4) of mothers were in the NHSP cohort and 9.6% (3) of mothers were in the non-NHSP group.

After diagnosis, the detail of the Australian mothers’ choices about early intervention programmes emerged from the interviews, although the timing of mothers’ enrolment into programmes was not always clear from their accounts. Australian mothers were busy with appointments and whilst some mothers said
they contacted an early intervention programme as soon as their child was diagnosed, others focused mainly on the next steps important to them. For the mothers of late diagnosed children, this seemed to be more about their engagement with medical appointments and cochlear implant programmes. Of the twelve deaf children in the non-NHSP cohort, five were referred directly to a cochlear implant clinic and seven were fitted with hearing aids first. Four children from the ‘hearing aids first’ group were referred some time later for a cochlear implant assessment by Australian Hearing and an ENT made a referral for the remaining three children. Only four of the mothers in this group mentioned an early intervention programme whilst talking about the next stage. The mothers of the three babies diagnosed through the newborn hearing screening programme were referred and became involved with a cochlear implant programme.

One third of Australian mothers specifically mentioned their enrolment in an early intervention programme. As there was a possibility of cochlear implant surgery much sooner after diagnosis for these mothers than those in the UK, it could be that the Australian mothers viewed the assessment phase of a cochlear implant programme as fulfilling their need for early information and support, which in the past, was a function more usually associated with early intervention programmes.

The qualitative data revealed that mothers in both the UK and Australian cohorts consulted with a range of professionals when making their decision to have a cochlear implant. Figure 4.13 illustrates the numbers of professionals involved with mothers.
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Figure 4.13  The distribution of mothers’ professional relationships at the time of making decisions to have a cochlear implant.

As most mothers in Australia reported they had simultaneous appointments with a cochlear implant clinic soon after diagnosis these data suggest, given the number of consultations that it may have been impractical or impossible to enrol in an early intervention programme. For mothers A9 and A10, this was the case as the pre-cochlear implant phase was ‘linked’ to their early intervention programme and occurred at the same centre. Mother A11 chose a centre-based programme and called her early intervention worker a therapist. She spoke about the support of the therapist for the child as she waited for a cochlear implant. This mother also talked about the relationships she had with individual professionals who made up the assessment team at the cochlear implant clinic. Specifically, the mother viewed the audiologist and the ENT specialist as part of her early intention team and the degree of trust invested in these relationships is evident from this extract.

Yes,...because if they're telling us that this is the right thing to do then we are putting all the trust in the world to them and that what we think and they do this a lot more than we do and we're going to go with what they say. We felt very much that we could take what they say as being the right thing to do. (A11)
Mother A6 chose a programme according to her view of what her child needed at the time, which was therapy and signing. She chose a home-based programme.

…and they provided a weekly therapy service and you know obviously we wanted that for ‘Child’. ‘Child’ was already 13-14 mths behind in language development so for us it was pretty clear that we wanted to spend a good amount of time on intervention for her, to get her back up to speed. (A6)

After the child was implanted, the mother then changed to an oral only approach with a different programme. Of making the change, she reported that it was difficult to break away from the first programme and she felt as though she was “cheating”.

…… because of the training they provided me with all the support that we needed in the initial stages you know? ‘Child’ was obviously very frustrated because she couldn’t communicate then as soon as we started learning sign and she picked up on it really really fast, everything started changing, her behaviour and the frustration was finally being removed so I felt bad because you know they may have looked at it as though we were a short term option to them. Unfortunately we didn’t get the support from ‘programme’ to progress down the pure verbal path even though they had the oral aspect to their sign but they’d walk into our house and say ‘OK today we are going to switch off our voice and we’re going to purely sign’. I’m not comfortable with that. (A6)

Mother A7 also reported changing programmes according to her perception of her child’s needs. The change in this case, to move from a hospital audiology programme to a specialist centre for pre-school hearing impaired children, was an easy decision because it was better equipped for pre-school deaf children and had a shorter waiting list. The mother believed that continual assessment of hearing aid wearing was unnecessary; the assessment process was moving very slowly at the hospital, which prompted her decision to move.
But then after the first couple of follow-up appointments when you’re having your results coming back 90+ and it’s like ‘OK’ and it just kinda of came naturally where we’re headed and we don’t want to be bothered with hearing aids and this is such a waste of time and so why are we doing these silly puppets in this room when Child’s cheating and she knows what’s happening next so she’s going to prompt herself or pre-empt a reaction. How do they know that that’s scientific and just come on, give us this implant you know and we’ll push and push and we pushed. We talked to the hospital audiologist and we thought this is taking too long so we switched over [to the specialist audiology clinic] at X centre who said, “we’ll do it in three tests” They had the meeting and we had the answer. (A7)

Once the cochlear implant assessment phase was completed, the mother reported that she moved back to the hospital audiology department and enrolled in a different early intervention programme. Interestingly, the mother explained that she felt “safe” in her new programme the essence of which was twofold; first, each child was special and second, the programme was well resourced to meet individual needs. Importantly, she added also that there was not a high turn over of staff; workers were reliable and listened to what parents said they wanted.

Mother A1 said she chose the programme because it was only the one open in the holidays because she wanted to do things as quickly as possible.

So when the early intervention people said ‘I could come in a fortnight ‘or ‘it’s Christmas at the moment’ and we can’t come for 3 weeks or ‘we’re closed at the moment’ I just found all that totally heartbreaking and then I rang [Programme Leader] and she said ‘I’ll come tomorrow’ and that was fantastic. That was what I needed. I just needed someone to come and talk to me and explain things through for me a bit more and help me understand what was going on because I felt completely lost. (A1)

Two mothers reported that their cochlear implant programmes became enmeshed in the early intervention programmes that they had chosen. One mother (A3) said that she would have preferred it to be “a little bit more
together”, as often the same issues were dealt with in two different settings and opposing views surfaced. She felt that the hospital practitioners lacked empathy with her point of view, however she excused them, recognising that it was their “day to day job” after all.

….but for a parent it’s much more. You want to discuss it more than once so you that know. Maybe they’ve just grown a little too accustomed to what they do and how they do it and they’ve said it a hundred times whereas you’re hearing it for the first time.

(A3)

A second mother (A5) said that she chose her early intervention programme because it offered an oral approach and she wanted her child to talk. She reported similar feelings to mothers in the UK when her baby refused to wear the hearing aids and she was critical of the intervention programme. She said that the focus was disconnected from the issues that troubled her and remote from her child’s communication needs. The programme teachers had different styles and A5 said that it was difficult for her to adjust to a style that was contrary to her own. She said that she wanted a teacher who arrived on time, with activities organised and focused on a particular issues jointly chosen. As she struggled with the hearing aids, an audiologist from Australian Hearing told her that only a cochlear implant could give her son “a chance to talk”.

Mother A2 reported that she received home visits from more than one organisation. Her appraisal of all the support she received, which included emotional support from a hospital based ENT, was that it was solely child focused.

So that’s good on the one hand because she needs the help. She’s the one with the problem then lets focus on her but there was nothing for us. So a pitfall in any of this is there is no real support there for the parents to deal with it any of this and I think we’re lucky in our case that we’re both fairly level headed people and you know….kept ourselves on track and we’ve managed to keep our marriage together through the ups and the downs. (A2)
In the NHSP cohort, the mothers’ accounts of their engagement with an early intervention programme were all different. Of the three mothers with newborn babies, one mother (A3/scr) received regular professional telephone support from the screener who had accompanied her to the diagnosis. She said that she used the Internet and took a one-day at a time approach to managing medical appointments before choosing a home-based early intervention programme. Although her baby was fitted with hearing aids, it was assumed from the start, and there was never any doubt, that she would be a candidate for an implant and this mother questioned the need for continuous assessment in this regard. The mother said that she perceived her role to be to slow all the events down; she believed routine was important for babies so she cancelled appointments if her baby was overtired or unwell. When implant surgery was offered at six months of age, this mother declined.

They would have operated on her when she was 6mths old and I was not keen for that at all she was just too little… like she wasn’t a small baby compared to other babies but to me she was just too young and frail so I sort of wanted to wait until she was about 10 or 11mths old and luckily I got that…that just happened. But I would have imagined if they had called her up at about 9mths I wouldn’t have had a great deal of choice it would have been ‘yes, you’re having it now or you go back on the waiting list’ don’t know when you’ll get another opportunity. Fortunately that didn’t happen actually she was almost 11mths. She was over 10 mths. (A3/scr)

Mother A2/scr identified waiting for appointments as problematic. As previously reported, this mother had well presented positive information at the time of the diagnosis. However, the type of information did not address her needs. It did not help her develop a wider understanding about deafness. She stated that no one appeared to understand what she was going through and talking about herself she said that “there was nothing for a long time”.

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It was like decide…choose…choose an early intervention centre and I went along to the playgroup but the mothers were all running round after their children, they were so much further along in the process and I just felt very alone holding this baby and I just put him on the floor, there wasn’t even a couch for you to sit on with your newborn, just this mat. (A2/scr)

She chose a therapy-based programme, which, she said, fell short of supporting her and her everyday communication with her child.

I think there should be more about the big picture stuff about deafness.// Sure the one to one sessions are great but we never really talk about my life with ‘Child’ day to day and how he communicates.// I know that everyone communicates in different ways and there is no one way but we can’t do AVT [Auditory Verbal Therapy] all the time when we are just at home and communicating normally can you? (A2/scr)

Mother A1/scr said that to find appropriate services and support you needed to be in the “right loop”. Having little social contact other than going to appointments during the first year was difficult. Gradually she discovered services by herself although Australian Hearing eventually provided a list of options for programmes. She said that overall, what worked was to “put my best foot forward and not wait to get answers”.

In summary, not all Australian mothers enrolled in an early intervention programme immediately. At some stage mothers discovered that they had options and different services to choose from and it was difficult to establish the exact timing of mothers’ engagement with early intervention practitioners as some of the pathways were fused with pre-cochlear implant assessments. As mothers began to grasp the impact of deafness on their child, the interview data revealed that different professional perspectives influenced the mothers’ decisions. However, as the mothers’ needs changed, so they opted for programmes that had the best fit with how they viewed the needs of their child at the time.
4.16 Summary

Mothers’ accounts of the diagnosis of deafness and their involvement with professionals were unique experiences. Quantitative data reveal a timeline of events linked together in a linear way. However, interview data suggest that mothers’ experiences, whilst reflecting a linear pattern, are a series of steps and stages where the flow depended on many factors.

This research was conducted at the intersection of two systems for the early detection of hearing loss in young children. Whilst the distraction test technique was still the practice of choice in the UK, in Australia, the rollout of Newborn Hearing Screen Programmes using new technology was current only in selected birth hospitals, and little evidence remained of previous screening practices. The findings reveal that mothers were alert to their babies’ ways of responding to sound and more than half of the Australian mothers (n=53) in this study needed to raise a concern about their child’s hearing problem. All these mothers were accurate in their assessment of the babies’ hearing. The interview data show that except for the mothers who consulted private audiologists, all the mothers who raised a concern about hearing failed to convince a professional of a problem, ‘Wait and see’ and reassurance were typical of clinical responses to mothers’ concerns.

Mothers’ stories in both the UK and Australian non-NHSP cohorts unfolded as three steps. First they raised a concern, second they obtained a referral to audiological services and third, their babies’ hearing was tested. The time taken between the steps was variable and often led to delays in diagnosis. Mothers with babies identified as a result of NHSP were referred for further audiological assessment and diagnosed in the first few weeks of life. However, four mothers and babies discharged from hospital, believing their babies to be hearing, needed to raise concerns later in similar ways to the non-NHSP mothers. All the mothers discovered their babies to be deaf.

Irrespective of how the diagnosis of deafness occurred, it was an unexpected event for all the hearing mothers, who were all deeply shocked at the permanence of sensorineural hearing loss. Deafness challenged mothers’ expectations of the future and the ways they thought their lives would be. The
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ways mothers interpreted the news varied according to their experience, information and personal histories. Mothers reported less anxiety and more positive experiences of the immediate time after diagnosis when they had someone with them or a professional took the time to talk to them after the diagnosis.

Mothers’ first challenge subsequent to the diagnosis was their child being fitted with hearing aids with mothers’ responses to hearing aids being variable. Since then the beginning of the research study, cochlear implants have become available as an alternative listening device to hearing aids for profoundly deaf babies. All the mothers in Australia, irrespective of the method of detection of hearing loss, engaged with a cochlear implant programme at a stage soon after diagnosis and the fitting of their child’s hearing aids.

From the mothers’ perspectives, finding out about services and the coordination of service provision differed in the two countries. In the UK, there was only one model of service delivery and all the mothers received a home-based service immediately after diagnosis if it occurred in school term time. In Australia, hearing aids were fitted by one service and mothers needed to choose any other service they wanted. Mothers’ interpretation of key professional messages, regarding, for example, hearing aid wearing or strategies to develop language, audiological terms and the jargon of deafness at times affected their interpersonal communication with specialist practitioners. Mothers’ perceptions of services depended on how they related to both their own needs and those of their children.

Whilst delay and waiting characterised the early stages leading to a diagnosis, these research findings suggest that after diagnosis there were also systemic delays, e.g. school term holidays in the UK prevented teachers from home visiting or Christmas/annual holidays in Australia meant services were closed and inaccessible. Following diagnosis, Australian mothers had many issues to consider especially if hearing aids were of little benefit to their child and the data revealed that mothers were involved in making complex decisions about the future from the beginning. As they began to understand the impact of delay on their child’s speech and language development some mothers made different
decisions, e.g. changing to an early intervention programme with a pre-assessment cochlear implant programme to avoid hospital delays or to reduce the number of sessions required to establish eligibility for surgery. The findings highlight, first the need for skilled, empathetic and sensitive practitioners and the importance of personalised information and second, flexible systems that reflect a sense of urgency when a concern about hearing is raised.

The interview data provided the researcher with privileged information. Mothers’ experiences of raising concerns, diagnosis and their journeys to become mothers of deaf children are unique stories about change, adaptation and connection to primary health care systems and specialist early intervention services. The rich content of each mother’s particular story challenged the author’s current understanding of the process of diagnosis of hearing loss; clustering the emergent themes enabled a reconstruction of the manner in which hearing loss is identified according to each phenomenal element contained in the mother’s accounts.
Chapter Five: Discussion

This chapter draws on both the quantitative and qualitative findings from chapter four to discuss the experiences of mothers when they discover their child’s permanent hearing loss. This research was conducted in the UK and Australia at the intersection between a previous programme of hearing loss detection — the distraction test — and the implementation of a mandated newborn hearing screening program at selected sites in Australia.

Consistent with a narrative inquiry, writing about human experiences must emphasise the development of phenomenological understanding and the order of meaning as being connected with what is already known (Crossley, 2000a; Polkinghorne, 1988). Once the themes that emerged from the data were identified (Smith & Osborn, 2003), a preliminary observation was the sense of a normal flow between the events which contextualised the process of diagnosis. The interruptions to the flow were the points at which mothers asked, ‘what does this mean?’ For the purpose of this discussion, mothers’ stories are clustered in ways which preserve the individual integrity of each case, yet disclose patterns of experience that related to their encounter with each professional (Gadamer, 1976b; Lincoln & Guba, 1990) or a significant point in the early identification process. The current research has shown that the period of time from when a concern about a hearing problem was raised to the point of diagnosis can be protracted. From a systemic perspective, the conversational interviews with mothers highlight the clinical complexity of the procedures to identify hearing loss, but they also expose the process as a series of steps and stages with variable rates of detection. Mothers, positioning themselves as the primary carers, recall the process as a sequence of chronological events, managed by different service providers, which were linked by referrals and often characterised by delays.

Insight gained from the mothers’ accounts illuminates how their personal journeys may contribute to the body of knowledge around the diagnosis of deaf children in five ways. First, it contributes to an understanding of what it is like to become a mother of a profoundly deaf child after giving birth to a baby that seemed normal in every way (Feher-Prout, 1996; Hyde, 2005). Secondly, it adds
to what is already known about the importance of parental concern in the detection of deafness (Coplan, 1987; Elssmann, Matkin, & Sabo, 1987; Gregory, 1976; McCormick, 1983; Robertson et al., 1995) and draws attention to an unaltered professional view of a mother’s concern despite recent literature. Thirdly, it identifies how different professional perspectives shape mothers’ understanding of permanent sensorineural hearing loss. Fourthly, it illuminates some positive systemic changes that have taken place in public health systems for the early detection of hearing loss early. Finally, it highlights the need for skilled practitioners with levels of technical expertise commensurate with skills in communication.

From an interpretative phenomenological perspective, mothers are situated socially and morally in their family, in their personal histories, and culture, constituted by their duties and responsibilities to their child. This local moral order predisposes mothers’ approach to professional services; their actions were lived according to a subjective view constituted from past experience and understanding (van Manen, 1990). The literature suggests that systems of intervention following diagnosis rely on mothers’ relationships both with their babies and with professionals to evaluate the performance of health and family service support (Davis et al., 1997; Roush, 2000). Davis proposed that the diagnosis and fitting of hearing aids is “actually a lifetime process of multi-agency care with the family and the child at the centre” which suggests that families require ongoing support and care from a range of practitioners starting with hearing aid or listening device fitting. However, the findings of this study foreground the different ways mothers engaged with and interpreted the various contexts of clinical consultation, which guided their next clinical encounter. These were unique rather than generalised experiences of becoming a mother of a deaf child.

Essentially, it was found that the experiences of mothers in either the non-NHSP or NHSP groups were not dissimilar except from the point of view of who initially flagged a first concern and the time it took to confirm a hearing loss. New terminology and confusing jargon constructed different world views of the deafness problem and mothers needed time to adjust to their deaf child in their own ways. A hearing family’s adjustment to a hearing loss in a baby or young
child is not a new concern (Gregory 1976; Young, 1999). Since the implementation of newborn hearing screening, Young and Tattersall (2007) argue that there appears to be a changed set of circumstance through which professionals understand families’ experiences of deafness. Whilst each mother’s view of her relationship with a health care practitioner, her audiologist, teacher, or specialist was unique, common themes emerged from the mothers’ stories of their experiences to highlight how a diagnosis unfolds.

In addition, a third group of mothers emerged from both screened and non-screened cohorts during the course of the study. These were mothers of children with otitis media with effusion (OME) whose experiences of the detection of an underlying sensorineural hearing loss were highly variable. This was accounted for not only by inherent systemic delays, but also in the ways in which mothers’ own perspectives of this conductive condition confused their expectations of their child’s speech and language development.

In keeping with the organisation of the study thus far, the next two sections follow a similar order to the previous chapters, which is to discuss both the UK and Australian mothers’ experiences from the non-NHSP cohorts first and then those of the Australian NHSP group. As other points emerge they will be discussed in detail pertinent to the literature. Finally, in the last section, the discussion focuses on a research interpretation of the mothers’ conversations with the author (Gadamer, 1976a), to provide further insight into how the diagnosis characterised their understanding of permanent hearing loss.

5.1 Raising a concern - mothers in the non-NHSP cohorts (UK and Australia)

An expected finding was that nine months of age was a pivotal moment for a developmental concern to be raised about a potential hearing loss (Bowlby, 2005; Bretherton, 1992; Ewing & Ewing, 1944; Whetnall & Fry, 1971). However, even though children at this age were targeted for hearing screening using distraction techniques and patterns of maternal concern were also concentrated around this age, many mothers were concerned about their babies’ hearing earlier than this.
5.1.1 Mothers’ concern earlier than six months

Mothers retrospectively attributed this intuition to a “sixth sense” or their “gut feeling” that their babies were responding to sound differently from expected. Bowlby’s attachment theory can provide some valuable understanding of mothers’ expressions of unease in these early circumstances. Bowlby (1965), proposed that infants are social beings who relate to their mothers from the start and rejected the notion that infants only connect with their mothers for oral gratification. According to Bowlby, a mother intuitively lays down her brief or outline for social interplay, which is effectively her unique blueprint for social interaction with her baby. In this current study mothers became concerned when their baby’s responses deviated from the blueprint. Initially mothers were unable to say what was particularly awry or “not right” and so their levels of concern wavered (Watkin, Baldwin, & Laoide, 1990). For some, speculation ended in a pivotal moment, such as when their baby did not respond to sudden loud noise. It was at this point that mothers sought professional help.

5.1.2 Professional responses to concerned mothers in the UK: health visitors, distraction testing and test performance

In the UK, when a mother raised her concern before the time of a scheduled HVDT, it did not help her gain earlier entry into a formal audiologic testing situation. Instead, a referral to audiology services was conditional upon a baby having reached the age of nine months then failing the distraction test two or three times (Bickerton & Beagley, 1981; McCormick, 1983). This was an important finding as the literature is persuasive in suggesting that parental concern needs to be taken into account (Coplan, 1987; Johnson & Ashurst, 1990; Robertson et al., 1995). For that reason a second question can be asked here. Why was a mother’s concern not taken into account?

The HVDT was an important medical benchmark in the UK system for the early detection of permanent hearing loss. It relied on a primary relationship between health visitors and mothers and their interconnectedness (McCormick, 1983; Thayer-Bacon, 2003). In the current study, mothers’ experiences of raising a concern in the UK were of dismissive rather than responsive practices. They often felt their personal observations and inferences were ignored or disregarded. When any mother raised a concern about their baby’s hearing,
essentially what they wanted was, first, acknowledgement, and second, further investigation. If experienced mothers had an existing relationship with a health visitor, the protocols of the distraction test were varied and the test was delivered before the child was nine months old. Experienced and inexperienced mothers predicted that their babies would pass the HVDT, and this was almost always the case especially when it was repeated for a second or third time. Mothers said that their babies were “smart” and had learnt to do the test by picking up on clues other than the sound being presented. McCormick (1983) supported this view in his critical appraisal of test techniques when he referred to a child being able to pick up on a range of unacceptable environmental auditory clues, e.g., noisy clinic locations, rustling of jewellery, creaking of floorboards as well as visual and olfactory cues. Nevertheless, McCormick strongly supported and promoted the merit of the distraction test if the test protocols were strictly adhered to. He recommended that acoustic conditions, tester skill, particularly with respect to recognition of a child's searching techniques and the use of trial periods, without sound presentation, were important. On the other hand, Haggard (1990) argued that it was difficult for health visitors to follow detailed audiometric procedures when their roles essentially demanded a more generalised approach to young children.

These arguments suggest that the mothers in this study, who formed a view the test was imprecise, when it came to confirming their concern, may have witnessed any or a combination of the stated difficulties with the test delivery and professional error seems a likely cause for ambiguous or inaccurate results. Moreover, if the test was repeated on several occasions, as reported by the mothers, this possibly may have accounted for a baby becoming over familiar with the test routine and rendered false negative results. All except one of the mothers in the UK had concerns about their babies’ hearing prior to the test, which seemed not to have been taken into account.

For the mothers in the current study, their views of their baby’s test performance often contrasted with those of the health visitor, making referrals problematic. Advice was offered to the mothers as reassurance; however, many mothers were adamant about their view of their babies’ problem and they said they pressured the health visitors to force a referral to audiology services,
irrespective of the test results. This could support a view that not only were the protocols for the delivery of the test adjusted to respond to a mother’s early concern, but also that results were either altered or non-specific enough to allow the mothers smooth access and referral to a formal hearing test. Taking the findings from the current study, there is little doubt that, on occasion, babies’ distraction test results were recorded in a cloud of uncertainty on the one hand and influenced by a mother’s insistence on the other. This would appear consistent with the findings from a study conducted by Mott and Edmond (1994), who found that data relating to HVDT screening were inaccurately entered into the National Child Health Computer. Firstly, the authors found it impossible to determine the exact rates and patterns of referral. Secondly, they also found evidence of mistakes in recording whether or not the HVDT had taken place. Thirdly, there was confusion about the pass/fail results. This possibly explains why distraction test results did not correspond exactly to the pre-determined codes suitable for computer entry identified by Mott and Edmond.

In the current research, concerned mothers who accepted reassurance that turned out to be “poor” advice (Elssmann et al., 1987) experienced longer delays in obtaining a diagnosis (Rickards, Roberts, & Dennehy, 1993). Whilst concerned mothers in the UK deferred to health visitors in the first instance, which was central to the process of hearing screening from a systemic point of view, they were critical of the initial encounters. Mothers did not view health visitors as a source of support. Rather they were someone mothers needed to get past to obtain a referral. Hitchens and Haggard (1982) defined the role of the health visitor in this context as not specifically charged with identifying a child’s hearing problem, case by case. Haggard (1990) characterised this period of early distraction testing being carried out alongside “a continuous background trickle of detections due to professionals and relatives from birth onwards” (p.1194).

According to Scanlon and Bamford (1990), the distraction test identified a “respectable degree of detection for a system accepting referrals from a screening service” which supported the maintenance of the health visitor hearing screening programme. It was predicted that all referrals would include the infants with sensorineural hearing loss and real cases would be identified.
According to an analysis of the records of babies referred by health visitors for a full audiologic assessment, 77% of babies below the age of one year were found to have some degree of hearing loss. Of these babies 22% had conditions severe enough to seek an ENT referral of which 8% warranted immediate surgery. A further 3% of babies referred by health visitors required hearing aids.

Babies were tested two or three times to achieve acceptable referral rates that satisfied cost targets and avoided false positive results generated by transient conductive hearing conditions. Thus, failing a test two or three times was essential to the cost effectiveness of the system. This suggests a view of a health visitor as a gatekeeper, rather than one of a responsive practitioner taking action on mothers’ concerns at primary, social or healthcare levels, which resonated with the mothers’ experiences. Scanlon and Bamford (1990) supported this view when they argued that the distraction test was too difficult for health visitors to execute in the context of assessing the whole child within his or her family and taking into account parental observations.

...in many ways a rigid non interpretative screening test concerned with just one discrete sensory function does not sit easily within the broader role of health visitors, especially as the task of assessing a 7 months old’s responses to sound involves (as health visitors are fully aware) a complex set of largely unquantified and unquantifiable variables (p.481).

Mothers’ observations of their child’s distraction test performance were consistent with their own evidence of their babies’ responses to sound at home. In the literature, the protocols for the conduct of the test were clearly defined, yet mothers’ accounts suggest that professional practice and recording of responses were questionable. This could possibly be explained by a systemic imperative to reassure mothers first and/or postpone referral and wait and see. Davis and Wood (1992) and Scanlon and Bamford (1990) reported increasing disquiet about the reliability of the distraction test as a screening tool as referral rates increased, whilst detection rates and coverage declined. It may also be possible that health visitors had lost faith in the test’s capacity to flag a problem and this may have affected their ability to deliver the test adequately.
In this study, the experiences of mothers in the UK were of anxiety, stress and concern about their babies’ hearing. Johnson and Ashurst (1990) reported that mothers’ anxiety related to a screen fail and followed the type — ‘He failed the test but I know he can hear’. However, the reverse was found for the mothers in this present study as their anxiety related to — ‘he passed the test but I know he can’t hear’ and their concern was dismissed. All the UK mothers and babies in the present study who secured a referral for audiologic investigation after the HVDT received a diagnosis of permanent hearing loss and only then were the mothers’ concerns validated.

5.1.3 Professional responses to concern raised by Australian mothers

The Australian mothers in the non-NHSP group responded to their babies in similar ways to the UK mothers and their experiences of being concerned were not dissimilar. Australian mothers’ accounts convey a professional response that was capricious, depending broadly on an individual conversation between a mother and her chosen health professional. Professional responses varied. They were dismissive, sceptical, or acknowledged with a referral to audiology services.

The Australian quantitative data revealed that half the mothers were concerned about their babies’ hearing before six months of age. However, only 16% of mothers interviewed suspected their babies’ hearing problem during these early months. Australian mothers’ reports of raising a concern about hearing after the age of six months did not reveal a routine child health monitoring system, nor did they point to any special relationship with a particular child health nurse, as in the UK. A mother’s view of the process appeared to rest with how she viewed the problem, her individual network and her personal preference of who to ask, together with her personal determination to obtain a referral to audiology services. Three outcomes were noted.

First, some mothers reported that they were reassured and/or encouraged to “wait and see”. They were either asked to wait for six months or until their babies were 12 months of age. If “wait and see” is considered as professional advice, then according to Elssmann et al. (1987) mothers who were told to “wait
and see” received “poor” advice, as they were not referred appropriately based on their concern, which contributed to the delay in detection rates. Similarly, Rickards, Roberts and Dennehy (1993), in a study undertaken in the State of Victoria in 1990-91, found that professional sensitivity to parental concern played a part in delaying the referral of children suspected of having a hearing loss by their parents. These researchers also found that children referred as a result of parental concern alone, were diagnosed significantly later than those who presented with either risk factors or a test fail result from distraction type screening. This appears to confirm how delays in confirmation of hearing loss eventuated for these Australian mothers in this current study. As a result, being told to wait and the mothers waiting, delayed the diagnosis.

Secondly, in some cases, professional responses to mothers’ concerns took the form of random distraction testing with noisemakers used in informal settings and casual ways. As such there was no pass/fail criteria to be satisfied first. All the mothers who consulted their family doctors were referred for audioligic testing, and mothers and babies progressed to a next stage. According to the mothers’ stories, their deaf children were not disadvantaged because the distraction screen test was no longer in place. In fact the reverse may be true. The absence of formal distraction testing resonates with the experiences of parents reported in studies conducted in 1989 and 1991 by Robertson et al. (1995) where it was found that “doctors carried out their ‘own’ hearing tests in the surgery” (p.14). This possibly explains the patterns of minimal delay in the early detection of hearing loss noted in the quantitative data. If mothers who were concerned about a baby’s hearing in the first six months went to their family doctor, then they were more likely to receive a referral directly to audiology services. Further, as targeted at-risk screening was already in place at the time of this current research, it is quite possible that these babies were able to be screened using oto-acoustic emission (OAE) technology and their hearing loss was subsequently detected early.

Thirdly, in spite of a greater prospect of concerned mothers receiving a referral for audiological assessment from a general practitioner, such a referral to audiology services did not guarantee a full hearing assessment. As none of the Australian mothers had prior experience of distraction testing, as in the UK,
they were unprepared for what to expect or what the different types of test might entail.

5.1.4 Mothers’ responses to preliminary hearing tests in Australia

From a clinical perspective, the consultation is the site for the encounter and the interpersonal relationship between the clinician and ‘patient’ is fundamental to clinical practice (May, Dowrick, & Richardson, 1996) and a way of bringing together perspectives. This calls to account not only the system of audiologic assessment that was in place for the Australian mothers in this current study, but also the quality of the interpersonal communication and the information mothers received about the particular tests used in full hearing assessments in young children.

A traditional model of audiologic assessment and practice positions the parent as a “passive participant” (Gravel & McCaughey, 2004). In general mothers arrived in the audiology clinics holding a common view that a hearing problem could be fixed and their understanding of their child’s problem was as a temporary delay in speech or language development, which would spontaneously resolve with medical intervention. After a referral for a hearing test, the mothers expected results. Some mothers reported that whilst they believed, at the time, that their babies’ hearing was tested, in retrospect, they came to understand that only middle ear compliance was assessed using impedance or “pressure” tests. This group of mothers received ‘wait and see’ advice. If audiologists failed to differentiate adequately between the two types of tests for conductive and sensorineural deafness conditions, one could speculate that the mothers who received this advice preferred this result and they heard only the information about a temporary condition, which had a good fit with their beliefs about hearing problems in young children. Such results also met the mothers’ expectations of this type of encounter and their concern for their child was momentarily set aside. However, if their views of their child’s problem seemed not to have been fully explored by testing to confirm the mothers’ observations of their child’s poor responses to sound, then it is understandable why some mothers became confused.
5.1.5 Australian mothers, otitis media and a “wait and see” approach

Given the prevalence of otitis media in early childhood (Finkelstein et al., 2005; Roberts et al., 1991; Russ et al., 2005), it is possible that in some cases only this condition was tested for. This group of mothers received ‘wait and see’ advice. “Watchful waiting” is a particular clinical approach to managing otitis media (OME) that avoids the use of antibiotics (Finkelstein, Stille, Rifas-Shiman, & Goldman, 2005). The authors noted that this approach assumes first, a relationship with a parent and an agreement to manage the condition together, and second, that the condition is not severe. However, the mothers who received this type of information reported that they left the clinic with little understanding about the type of test conducted, what had been measured or what to expect next. In the current study, mothers who used the language of conductive hearing loss had descriptive information that was appropriate for this temporary condition, yet without the supporting relationship described by Finkelstein et al. with respect to its future management.

That audiologists, in this current study, employed a conservative “wait and see” approach towards the assessment of children, where mothers raised concern resonates with the findings of a study conducted by Rickards, Roberts and Dennehy (1993). These authors found that in 30% of cases, audiologists took more than three months to diagnose a sensorineural hearing loss and contributed to the delays in diagnosis. Luterman (1985) went further when he suggested that audiologists could induce parents’ denial if “proper clinical procedures” were not undertaken, which was interpreted to mean the ways in which an audiologist engaged with parents’ beliefs about hearing problems and their communication during the diagnostic process. This current study reveals that such issues still remain today.

Nevertheless, none of the Australian mothers who were told to “wait” waited for the full time specified by the professional. As mothers’ concerns increased, their perception was that the tests were wrong and they initiated their own return to audiological services. This endorses the view emphasised by Gravel and McCaughey (2004) that after
“one unique and often emotional parent-professional relationship is over [and] the responsibility again falls on the parents to follow up on the recommendations at a new facility and/or with unknown professionals” (p.310).

5.1.6 The challenges of hearing testing for (non-NHSP) concerned mothers, past and present.

The systems in the UK and Australia presented different challenges for the mothers concerned about a hearing problem. In the UK, at the time of this research, distraction test screening was part of a national system to monitor child health and development and children needed to satisfy entry criteria, which undoubtedly slowed their access to audiology services. In Australia, where selected birthing hospitals had implemented newborn hearing screening programmes (NHSP), the findings suggest that routine distraction testing for babies, aged eight months had already ceased to exist in other areas. Australian mothers and babies could be considered disadvantaged in these regions, as they needed to become aware of their own child’s hearing problem and raise a concern. Clearly, this study reveals that in the past, in the UK and currently in Australia, maternal concern alone afforded little benefit in terms of a child’s access into systems to identify sensorineural hearing loss. For Australian mothers, however, their view of deafness as a medical problem may have enabled a speedier referral and access to an audiology service in the first instance, although, evidence of middle ear/conductive problems prevented an immediate diagnosis. The major insight of this research is that contrary to recommendations in the literature in the last twenty years in both countries, mothers’ experiences reveal an unimpressive record of professional acknowledgment of maternal concern. The implication of this is revisited in the context of newborn hearing screening programmes.

5.2 Concern about hearing loss for mothers in the NHSP cohort (Australia)

The quantitative results showed that 75% of the neonates in the NHSP cohort were diagnosed before they were four months old. On the surface, the influence of a newborn screen on the early detection of hearing loss was evident. In the context of population screening protocols, the mothers interviewed knew about
tests for congenital and developmental disorders. However, not all the Australian mothers knew of the existence of the newborn hearing screen neither had they prior information about the tests. Similarly Vohr et al. (2002) found that despite multi media information about hearing screening before and after mothers’ admission to birthing hospitals only 29% of mothers with newborns and no mothers of infants who presented for re-screening know of the programme. Of the mothers interviewed (n=6), three received a diagnosis of hearing loss within the first two months after their baby’s birth and the other three needed to raise a concern later in ways similar to those already reported in the non-NHSP cohorts, before a diagnosis was reached. An NHSP failed to detect a hearing loss in these three cases and the interview evidence from these mothers with babies diagnosed later is worthy of note in the context of this current research study. For instance, one baby, who had a screen fail result at birth, was referred for audiological investigation where ABR results were misinterpreted and filed away without informing the mother. A second mother consistently raised a concern at her local health clinic from the age of six months onwards and the child was diagnosed at four years of age and immediately received a cochlear implant. A third baby had a deteriorating condition, with the NHSP only partially flagging a concern at birth when inconsistent results were dismissed by screeners as unremarkable. A fourth mother discovered that her baby had not been screened, contrary to her belief, when her second baby was born thirteen months later. On this occasion she was informed that the equipment had failed and newborn hearing screening was no longer available at the hospital. These findings are discussed separately in section 5.2.2.

5.2.1 Concern raised by screeners at birth

For the three mothers with newborns detected at birth, the conduct of the test, timing, and communication of the results were different for each mother. A surprising finding was that screeners reassured the mothers of babies with positive screen results in similar ways to the health visitors in the UK after conducting distraction testing (HVDT). Screeners made excuses about the equipment and referred to the likely causes of a positive screen result to be “fluid” or “blocked ears”. The mothers in this cohort confirmed that whilst they
accepted the results of the test, they also accepted the reassurance offered to them which was in contrast with mothers in the non-NHSP group. They were optimistic and unconcerned about a ‘fail’ or ‘refer’ screening test result. This resonates with the findings of a study conducted by Magnuson and Hergils (1999) that mothers whose babies failed their newborn hearing screen were reassured by screeners, although later, on retesting, these babies were found not to have a hearing loss.

In the current research, a mother’s acceptance of the refer result and re-testing appeared to be related to her experience and generalised prior knowledge regarding 1) family history or risk factors for deafness, 2) the meaning of ‘pass/fail’ in a screening context, or 3) babies’ unpredictable behaviour. These comments are consistent with those of respondents reported in a study conducted in the UK by Young and Tattersall (2005). In the current study, screeners used a wider variety of generalised or non-specific terms which Roush (2000) argued are problematic, in the communication of screen test results. Although mothers with babies with a “fail” or “refer” result were generally positive about the screening experience, they reported some negative views that focused first, on the number of times the test needed to be performed, and second, on the information given at the time, particularly that the term ‘inconclusive’ possibly could mean that a baby had a hearing loss. Both these views echo those of mothers reported in the Magnuson and Hergils’ (1999) study whose babies were recalled. A third view reported by mothers in the current research was the fact that results did not indicate the level of the problem.

According to the quantitative data, for the mothers with babies who received a fail result in hospital, referrals were organised at intervals, which appeared to be evenly spaced with diagnosis occurring within the first three months of life. In the interviews however, the mothers reported appointment patterns for re-testing that included many visits and some waiting, which when taken altogether these events amounted to a stressful time. As all the babies were subsequently implanted, it is possible that the mothers’ overall recall and view of events were complicated by simultaneous visits to Australian Hearing and/or a cochlear implant clinics where further assessments and confirmation of results required
repeated audiologic testing. JCIH (2007) recommend that the birth hospital is a key member of the team in collaboration with early hearing detection and intervention (EDHI) services. With respect to roles and responsibilities it is stated that hearing screening information is transmitted promptly to ‘the medical home’ and to the state EDHI coordinator to ensure that

…parents and primary health care professionals receive and understand the hearing screening results, that parents are provided with appropriate follow up and resource information (p.899).

Whilst the numbers of mothers here are small, these stories reflect the points raised in the critique by Wake (2003) rather than the good practice suggested by JCIH the Australian Consensus Statement (2001).

5.2.2 Professional responses to concern raised at a time later by mothers of babies screened at birth

A newborn hearing screen failed to detect a hearing loss in four cases. Each of the mother’s stories in this group was different and entering the system for audiologic testing was equally difficult for them all. Although one mother reported her confusion about the interpretation of ‘inconsistent’ or ‘slow’ NHSP results at the time of the hearing screen, retrospectively, the mothers who held a view of perceived hospital error did not conceal this detail.

For the mothers concerned about their babies’ hearing after a newborn hearing screen, a professional response was often slow and lacked a sense of urgency. Professionals either offered reassurance or were dismissive of the mother’s evidence. Although it could be said that OME hindered an early diagnosis for two of these mothers, the medical approaches taken to determine the exact nature of the problem and possibly to exclude a sensorineural component were variable. For one mother, it was an automatic procedure, to conduct an ABR under general anaesthetic during a myringotomy, which resulted in a diagnosis. For the second mother, notwithstanding her own professional background, she needed to both propose and insist on an ABR being conducted during surgery. This mother’s account foregrounded three other negative factors that interfered with the process to confirm her child’s deafness that highlight a lack of systemic affiliation with the rationale that underpins early diagnosis. First, the sluggish
professional engagement with her concern, second, the blaming of her child’s abilities and perceived developmental delay as a professional justification for poor test results, and third, the professional error in the interpretation of her baby’s original newborn hearing screening results.

For a third mother, the professional response that looked at a child’s uncooperative behaviour and her ability to complete a hearing test as ways of blaming the child for inconsistent results constructed a different problem. Developmental delay and/or autism were views proposed by audiologists and a family doctor to explain a child’s poor test performance and inconclusive results. The tenacity of this mother and her belief in her own day to day evidence of her child’s poor auditory behaviour increased her resolve to seek a professional who might share her view. This involved frequent consultations with and changes to practitioners until she reached a place where her views were taken into account, which resulted in a lengthy delay in obtaining a diagnosis. Retrospectively, a fourth mother concerned about her child’s hearing, received a diagnosis from a private audiologist of her choice and judged the hospital administrative system to be at fault for failing to notify her of the withdrawal of newborn hearing screening services. Although raising a concern with either a child health nurse of her family doctor and being reassured also accounted for this situation. Given these four mothers’ experiences and this current research evidence with respect to mediocre acknowledgement of maternal concern overall, a further question needs to be asked with respect to a safety net of hearing testing. Without maternal concern and a distraction test, what system is in place to identify hearing loss in children screened at birth whose hearing loss is missed or who develop a hearing loss in the early years?

5.3 How mothers’ experiences characterise the detection process

Bronfenbrenner’s (1979) ecological conceptualisation of nested systems is useful to help explain how professional practices located in different systems established the tenor of mothers’ relationships that affected their expectations of developmental checking and clinical care. Infant health systems (mesosystems) are inherently relational. In the UK, health visitors were an integral part of a mother’s primary network interconnected through the mothers’ experiences of health practice. In Australia child health nurses did not figure so prominently in
mothers’ accounts of asking for help. Nevertheless, from a systems’ perspective for first time mothers, health visitors/child health nurses were a public source of information and technical knowledge predicated on trust and an explicit institutional commitment to early intervention and disease prevention (Department of Health, 2006; Mechanic & Meyer, 2000). Central to any discussion about a mother raising a concern with her primary health care practitioner, is her abiding desire to do the best for her child (Magnuson & Hergils, 1999).

In this current study, for mothers in the UK, the health visitor distraction test was used to screen the hearing of all babies and health visitor support was home based nested within a mother’s microsystem, in Bronfenbrenner’s terms. When these mothers raised a concern about hearing with their health visitors, someone they trusted, all the mothers were falsely reassured. Mechanic & Meyer (2000) argue that a core element of trust in the medical relationship is “the belief that the other has one’s best interest at heart” (p.660). Mechanic & Meyer examined the concepts of trust in the medical relationships among three groups of patients with complex illnesses. As patients had no way of evaluating the technical competence of their health practitioners then it was not surprising that the findings revealed that patients placed great emphasis on interpersonal competence. In the UK, from a healthcare system perspective, an exosystem, health visitors were mandated to deliver an HVDT and make cost effective referrals. A second question needs to be asked here. When nurses are embedded in a mother’s microsystem and trusted, to what extent does this type of social arrangement create a tension between the technical demands of hearing screening and child assessment and the care demands of an interpersonal relationship to interfere with the delivery of positive test results and the giving of bad news? Scanlon and Bamford (1990) considered this. In essence, if health visitors considered it more caring or socially responsible to reassure mothers about their babies, rather than engage with concern based on clusters of observations or a single pivotal moment of a baby’s lack of response to sound, then this is broadly what they did.

In the Australian group, the primary health care providers (a mesosystem of child health nurses and general practitioners) were outside a mother’s
immediate network or home environment and generally a family doctor was more prepared to make a referral based on a mother's evidence. Mothers who were told to ‘wait and see’ reported that they were happy to accept this advice.

5.3.1 Professional reassurance
Where mothers raised a concern about hearing, primary health care professionals universally reassured these mothers as a matter of course. Until a diagnosis, it could be said for the mothers in both the UK and Australian non-NHSP cohorts that their understanding of a hearing problem was in a state of flux. It was, typically one of being concerned, asking a professional for help and then being reassured. As a consequence, mothers’ views of what constituted enough of a hearing problem to be professionally acknowledged needed continual revision as a result of professional disregard for their evidence.

Mothers had mixed experiences of professional reassurance as it took different forms. First, reassurance was used to justify repeat testing or non-referral of a baby, e.g. equipment malfunction, “wax” or “probably has a cold”. Secondly, reassurance offered as a ‘wait and see’ approach was an effective delaying tactic, yet, as has been noted already, ‘wait and see’ has a specific clinical meaning in the context of OME treatment. A parallel can be found in the research into the purpose of reassurance with patients in rheumatology clinics in the UK (Donovan & Blake, 2000). Reassurance was found to be a critical medical task and physicians usually attempted to reassure patients following diagnosis. Patients, however, did not interpret the statements as reassuring if their perceptions were that the disease was already affecting their lives. Successful or unsuccessful reassurance was found to relate to the extent to which the physician had acknowledged a patient’s current degree of difficulty by using “appropriate and acceptable terminology” (p.544). For the concerned mothers in this current research, professional reassurance returned a sense of order only for a short time, which prompted them to act in any of three ways: first, to repeatedly ask the same professional, second, to choose a different route to audiology services e.g. seek a different test in a different town (UK) or seek a private consultation (Australia) or third, to gather more evidence, e.g. a pivotal moment that finally disrupted mothers’ views of the ways things should be.
The current research highlights the use of reassurance in ways that were dismissive of the mothers’ concerns, when their evidence was considered less reliable than the nurses’ own assessments and/or the distraction test results. Although it was difficult to determine the exact influence on the mothers’ interaction when they asked their health visitors for help, reassurance can be associated with early delays in hearing loss detection. Another question can be asked here. What were the other possible systemic influences on professional practice that led to mothers’ concerns being ignored? According to the rationales that underpin child health surveillance systems, conversations with mothers were central to primary healthcare relationships and the continuing care for mothers and babies. Apart from these relationships being shaped by social arrangements, the experiences of the mothers in the UK show that health visitors were institutional gatekeepers for the referral system; from this perspective the nurses controlled both the interaction and the outcome. If a professional view of congenital deafness was that it was unlikely or that the rates of false positives were too high, then such social responsibilities could be possibly be expected to influence the agency of primary health care workers.

Australian mothers reported similar encounters, although they were less likely to depend on a child health nurse, as general practitioners generally referred mothers and babies for audiologic assessment. In the context of developmental delay and a discourse of risk, a surprising finding was that all the mothers who approached their health visitors in the UK (n=5) and child health nurses in Australia (n=3) said their concerns were dismissed.

For concerned mothers, asking for help and looking for a referral to audiology services, was characterised by professional reassurance, a “wait and see” approach and delay. Implicitly, a mother being told to wait signalled a view that a baby’s hearing problem was non-urgent, notwithstanding a privileging of a professional view by the disqualification of a mother’s evidence in some cases.

5.3.2 The detection process and the clinical conversation
Some mothers talked about their own powerful emotions when their concerns were dismissed. Specifically, conflicting information, poor choice of jargon associated with referrals, for example the use of simplistic terms, e.g. “routine”
or “have another go”, to explain the next stage of audiologic testing were deemed unhelpful by mothers as they tried to reconcile their understanding of a hearing problem and their evidence with that offered by the professional. However, this research illustrates that mothers typically trusted their primary healthcare professionals to deliver practices that were responsive and caring. Middleton (1989) argued that the patient’s understanding of the problem is “at least as important as that of the doctor” (p.383). All the mothers with a concern about hearing in both the UK and Australian non-NHSP cohorts contacted a professional.

In the dominant grammar of conversations between mothers and primary health practitioners, the local moral order positioned mothers (with their child) as patients and failed to address them as agents (Harré, 1999). In the UK, health visitors had moral authority by virtue of mandated distraction testing and referral linkages invested to them by the state. Similarly, in Australia where mothers were disappointed or confused by professional communication of results, they felt in the local moral order of their conversations, that the practitioners lacked “capacity” rather than moral authority, to resolve tensions that arose during the social encounters that were fundamental and necessary to the process of hearing loss detection. Confusion and communication difficulty frequently arose when results were discussed. From the mothers’ perspective, professional agency in these practitioners was mediated exclusively by test results, which signed cause and effect relationships that did not correspond with their signing mediated by the behaviour of the child. The mother’s moral capacity likewise, can only be apprehended in a real world conversation with the practitioner, which also encompasses the mother’s reading of her child’s behaviour.

5.3.3 Waiting for a referral

Many mothers consistently recalled waiting for appointments and diagnostic assessments before the confirmation of hearing loss. Waiting characterised their early experiences and is consistent with the findings of other studies (Fitzpatrick, Graham et al., 2007; Harrison, Roush, & Wallace, 2003; Kennedy & McCann, 2004; Russ et al., 2004; Vohr, 2003). Whilst some mothers
accepted delays as consistent with their views of any other medical referral process, some mothers in this study, whose children were diagnosed after their first birthday or later, held a view that special referral arrangements needed to be in place for babies and young children when a concern was flagged.

5.4 Diagnosis

Mothers’ recollections of the diagnosis were vivid and there was no single way to deliver bad news that suited them all. However, the mothers in this research valued skilled communication and audiologists or ear nose and throat (ENT) surgeons who were able to engage with their perspectives. These professionals were held in high regard which foreground themes of empathy, sensitivity and caring. Mothers arrived at the diagnosis with their personal experience co-constituted by cultural and historical meanings and their most recent professional contact. Mothers in the UK were unconvinced by distraction test results and all except one had demanded a referral. In Australia, since newborn hearing screening tests became available in some local areas, distraction testing had ceased to exist as a technological tool to flag the presence of a problem.

5.4.1 Diagnosis and the audiologist

Overwhelmingly, the audiologist was central to mothers’ first experience of permanent deafness and they featured most in mothers’ accounts. Many mothers had been on waiting lists. For some mothers the realisation of a problem unfolded to connect with and confirm their own concern when they saw for themselves their babies’ poor responses to sound. For three mothers of newborn babies, machines yielded these unexpected results. It was important to all the mothers, both concerned and unconcerned, that the tests revealed a clear picture of the existence of a problem or not. Unfortunately this was not always the case.

From a diagnostic perspective, delivering results highlights complex issues in communication (Luterman and Kurtzer-White, 1999; Tattersall & Young, 2006). Whilst most of the later research literature refers to results of early hearing evaluation as a result of newborn screening, these current research findings, that include distraction testing results, suggest that there always has been an overwhelming need for the sensitive delivery of test results. This study reinforces recurring factors in literature for the need for sensitive, direct and
honest communication (Davies, Davies and Sibert, 2003; Sloper, 1996; Tattersall & Young 2006). That professionals needed to demonstrate both technical expertise and have empathy with individual mothers was evident, especially when the clinical conversation failed to uncover and address competing or discordant views about the nature of the problem as in the case of non-NHSP mothers who were already concerned about the existence of a hearing problem. As shown already in this current study, audiologists varied in their skills to effectively communicate the different test types. Similarly, a number of examples emerged where audiologists had difficulty delivering test results which echo the findings of Russ et al., (2004). For example, some mothers remembered audiologists who had poor engagement with small children, exhibited poor interpersonal skills, such as avoiding eye contact, or had difficulty giving the news about permanent deafness. In these cases mothers were referred again to a different service without comment. These findings suggest firstly, an unclear protocol concerning inclusive results, secondly poor practice in terms of a professional understanding of a mothers concern and thirdly unsophisticated interpersonal skills.

Mothers also remembered audiologists’ attempts in plain English to clarify the meanings of technical information, by making references to aeroplanes and vacuum cleaners or predictions about children being able to talk. These themes relating to clinical competence, communicative expertise and empathy resonate with parents’ preferences for skilled professionals documented in other studies that have inquired into parents’ needs and perceptions of diagnosis (Davies, Davis, & Sibert, 2003; Fitzpatrick et al., 2007; Luterman & Kurtzer-White, 1999; Russ et al., 2004; Sloper & Turner, 1993). Roush (2000) advised that

> If hearing loss is confirmed, reporting the results to the families must
> be handled with compassion, delivered honestly but conveying a sense
> of optimism (P.60).

Roush emphasised the individual needs of family members and the many ways they responded to different degrees of hearing loss. He stated that it was imperative that families leave the clinic with a hopeful view of what can or will be done to assist the child. The mothers in this current research, who were
offered an optimistic view of the future, said they preferred this approach. They said that it helped them, despite of their shock, to seek and embrace new information more easily.

For the mothers who arrived at an audiology clinic after a previous professional contact where reassurance about a hearing problem had minimised their concern, it was hardly surprising that mothers found the audiologic results confusing, especially when underpinned, in general, by their own beliefs that hearing loss was a fixable condition. Two mothers avoided the concern/reassurance bind and went directly to a private audiologist. Neither mother reported any confusion about the results of these tests as documented by other mothers in the study, which possibly suggests that the detail of the referral may have contributed to setting the context for the hearing testing in advance. Both these mothers made their own appointments and clearly indicated directly to the audiologist that they thought their child was deaf.

Following a diagnosis, three different types of practice worked well for some mothers. First, when audiologists allocated time for a discussion of results for mothers who were well prepared in advance for a potential diagnosis. Second, when audiologists worked in pairs. Third, when audiologists demonstrated well developed interpersonal skills and sensitivity to mothers. For example, one mother valued an audiologist’s sensitivity to her distress and inability to take in new information and accordingly he took charge of the next steps on her behalf to avoid further delay. However, it is noteworthy that for many of the mothers, any extra time taken after the diagnosis, to give albeit informal information e.g. notes written on an envelope or a pencil drawing of an ear, worked equally well in the short term in the absence of any other organised communication of information about deafness. These types of responses from audiologists illustrate a degree of empathy and understanding for the mothers in those moments following diagnosis. However, they did not occur consistently enough to be considered as an integral or formal part of the diagnostic process.

Mothers’ accounts foregrounded that a diagnosis was often a culmination of a series of stages of hearing tests, assessments or surgical events. In this way, each mother’s experience was unique. This strongly suggests, therefore, that for
each mother, when an audiologist made a diagnosis, the context of preceding events becomes both relevant and important to any conversation about the diagnosis. Results given in isolation without a connection to an individual mother’s previous encounter made it more difficult for her to understand the results. This seemed to be particularly pertinent in the cases of babies with OME. The views of audiologists could be explained in the ways that they perceived the purpose of the tests and the relevance of results in the context of each referral. This could have been firstly, to identify a problem as a response to a failed screen, secondly, to respond to a general practitioner’s referral or thirdly to confirm audiologic results already obtained. Whichever was the case, according to the mothers’ stories, communication was often limited to the results alone and social interaction appeared to have been largely eliminated from the encounter. It could be, as Gravel and McCaughy (2004) argued, that audiologists believed each consultation to be a single meeting and permanent hearing loss was unexpected.

5.4.2 Diagnosis and mothers’ responses

The mothers’ stories of their deep shock at the diagnosis of permanent hearing loss are typical of contemporary illness narratives in the literature when a diagnosis is an unexpected event (Charmaz, 2000; Frank, 1998; Kleinman, 1988). For example, Frank proposed that people enter into the “storytelling relation” (p.355) as a way of rebuilding themselves. Crossley (2000b) stated that it is in the “face of such incoherence that narratives and stories become important in another way” (p.541). When the connection is broken with what we know, then we attempt to rebuild it through telling stories and the use of narratives. In spite of the shock, the mothers in this study responded in different ways. Some, mothers felt the loss was permanent and that “life would never be the same”. Another mother said that her child was still the same person and that she needed to “get on with the job” and do the best she could. One mother said of herself after the diagnosis that she had a “different child” about whom she knew nothing, which strongly confirm views documented by other parents (Luterman & Kurtzer-White, 1999; National Deaf Children's Society, 2003).
In the literature, grief and loss have been identified in at least two ways, first, as sequential stages (Kubler-Ross, 1970), or second, as extended periods of chronic sorrow and despair (Lowes & Lyne, 2000; Olshansky, 1962). Typically, the staged approach to grief has variously been applied to mothers by professionals, as a way of identifying their progress towards recovery and adaptation to the shock of the diagnosis of permanent deafness and the “loss” of a hearing child. In this current study, a mother’s adjustment beyond the event, however, more closely resonated with the ideas of fluidity proposed by Moses (1985). This perspective supports an acknowledgment of a different child and a change in life circumstances rather than one of passive acceptance. Getting on with the job was a common sentiment expressed by mothers, which was reflected in the ways they took action and tackled the next stages.

The present research illustrates not only the range of mothers’ responses to deafness as an unexpected event, but also the diversity in their choices of what to do next. Some mothers preferred to be alone and find information by themselves, whilst others could not make the next appointment quick enough to obtain more information. “I needed guidance” or “I needed to know what to do” were typical of the sentiments expressed by mothers in all the cohorts. Most mothers focused on a need for action. Conversely, others stemmed the flow of information by declining visits or delaying contact with professionals. This was for two reasons, first as a way of refusing to hear more negative information about the way things were, (a mother in the UK), and second, because events were moving too quickly. Particularly for one mother (NHSP) a systemic push for urgency surpassed her needs as a new mother and the chain of the events overwhelmed her, and she took steps to slow the sequence of appointments down in favour of developing more realistic routines for her baby.

If a professional view of this type of response was of denial, then Luterman (1985) asserted this kind of “denial” can be viewed as a “coping strategy based on feelings of inadequacy and being overwhelmed by a problem” (p.57). Indeed some mothers revealed that they needed time after the diagnosis and could not contemplate leaving the house to find more information. Bowlby (1980) argued that the sort of loss associated with a diagnosis of a lifelong condition is complex, as it denotes a disruption to a significant attachment — the loss of an
ideal child. According to Bruce and Shultz (2002), a parent’s preoccupation with searching for that which is lost has all too often been simplistically “labelled as denial” (p. 10) by professionals.

5.4.3 Diagnosis and the next referral

The literature suggests that the early identification of hearing loss is of limited value without a comprehensive system of care (Fitzpatrick et al., 2007; Hyde, 2005; JCIH, 2007; Watkin et al., 2007; White, 2006). Wilson and Junger (1968) suggested that to demonstrate effectiveness and comply with the principles of population screening, services need to be in place to provide “authoritative follow up and appropriate intervention” After diagnosis, for all but three Australian mothers in the non-NHSP cohort, hearing aids were prescribed for their babies. Only two mothers in the UK waited for hearing aids due to a systemic delay caused by school holidays and the fact that education staff fitted hearing aids. In Australia, there were delays in the timing of next appointments to Australian Hearing to re-test and confirm preliminary test results for the purpose of hearing aid fitting. There were also delays to accessing services because of faulty referral and document transfers; all these factors required mothers to consistently keep abreast of the flow of procedural issues.

In a study undertaken by Young and Tattersall (2007) reported that parents had mixed responses to knowing early about deafness and similar trends could be seen in the findings from this current study. Most of the mothers who discovered early wanted to capitalise on a perception that they had gained time on the other hand, others thought they were losing time. The notion of a timetable put forward by Young and Tattersall was much in evidence in the current study’s findings in both groups of non-NHSP and NHSP mothers. In both groups, when referrals or appointments failed to materialise, some mothers told stories of telephoning agencies every day or confronting professionals. From a professional perspective, early hearing aid fitting following diagnosis (JCIH, 2007) was seen as an urgent next stage and indeed mothers in this current study felt an urgent need to progress through the system quickly. Being on a waiting list for a next appointment became very stressful. Conversely, for two mothers in the UK, visiting teachers of the deaf unwittingly promoted
unrealistic timelines, which compromised the mothers’ capacity to realistically communicate with their young children. As Young and Tattersall highlight the notion of a timetable can be a “source of pressure and further distress” (p.217).

For the Australian mothers with babies screened at birth, who understood a message of urgency at the time of diagnosis, delays in the next stage and/or hearing aid fitting was very stressful; they wanted to “get on with it”. This can possibly be explained that for Australian mothers in either cohort, a diagnosis of profound deafness often included a simultaneous appointment to a cochlear implant clinic. Although the pathways to either hearing aid fitting at Australian Hearing or to a cochlear implant clinic were often spoken about by the audiologist or ear nose and throat specialist, with urgency a key message, some waiting was involved as mothers shared the appointments system with others not necessarily involved in a newborn hearing screening programme. This perception of a lack of action by professionals was stressful for the mothers and confirms the need for expedient services (Gravel & McCaughy, 2004), a view endorsed later by McCracken, Young and Tattersall, (2008).

5.4.4 Diagnosis and information

Mothers often found initial information confusing. In the UK, mothers had opportunity for early discussions about deafness as immediately after diagnosis peripatetic teachers visited the house (Uus & Bamford, 2006). However, this was generally not the case for the Australian mothers in either the non-NHSP or NHSP cohorts in this current study. Their experiences suggest that having the information must be considered as “authoritative follow up” (Wilson & Junger, 1968) as there was little evidence to show that Australian mothers had support when making their choices about intervention services. Most Australian mothers mentioned Australian Hearing in the context of receiving more information.

There was wide variation in the ways mothers talked about information and on the whole mothers agreed that there was an abundance of information. In the UK, mothers received information from their peripatetic teacher of the deaf more or less immediately after the diagnosis in a one to one situation and for most this worked well. For some Australian mothers, on the other hand, information was confusing and not always relevant to their own situations,
because it was offered through books, leaflets, resource or contacts lists. Information given verbally was overwhelming for some and appeared to reflect the numbers of professionals with whom the Australian mothers had contact after diagnosis, because they said they wanted more personalised information, specific to their own predicament, their child and their view of the problem. Others said that they needed to hear the same information over and over again before it made any sense. Luterman and Kurtzer-White (1999) argue that parents need time to process information to understand the reality of a permanent hearing loss. A diminished capacity to process new information after a person is traumatised by shock or unexpected events had been previously recognised by Luterman (1984), and is highlighted again in the work of Bruce and Schultz (2002) and the findings of this current study confirm this view.

Mothers said they coped one day at a time. This finding is consistent with the literature that proposes a model of coping behaviour that depends on a “goodness of fit” between the reality and an appraisal of a situation for the development of effective coping strategies (Feher-Prout, 1996; Folkman, Schaefer, & Lazarus, 1979). Whilst the mothers in the UK had support in their homes, mothers from all cohorts reported their uncertainty about the future. Specifically, mothers in the UK valued information about hearing aids and strategic approaches to enhance communication of their babies on the one hand, although on the other, they consistently lost hope when the outcomes they hoped for failed to materialise. However, hope was more widely sponsored by professionals in Australia, and the cochlear implant seemed to be the basis for this.

5.4.5 Diagnosis, choice and early intervention

The literature suggests that many parents feel beset by the problem of deafness and Beazley and Moore (1995) and Marschark (1997) argue that the future with a deaf child challenges parents’ competence and this resonated with how mothers reviewed their options and made their decisions and choices. At a time when mothers were beginning to process new information, they were also being asked to make choices. Gregory (1995) asserted that the task for parents with newly diagnosed deaf children has become more onerous because hearing loss
is more ambiguously defined corresponding to diverse views and the many choices currently available. This present research adds to that view and reveals mothers’ reports of the pressure associated with this selection task.

In the UK, at the time of the research, mothers relied on hearing aids alone and expected intervention services to come from within the system, in particular the education department. For some mothers this service was supportive and their relationships with a peripatetic teacher of the deaf developed into one of mutual respect and shared understanding. For others, they felt challenged by the visits, which they perceived as interfering or having little to offer if the deafness was so severe. A lack of communication progress in their child was symptomatic of either a break down in the relationship with the teacher or reflected the need for a change to the approach used with the child, especially when mothers found out about a cochlear implant.

For the Australian mothers in this research, this was not the case and they identified a variety of sources of information that led to their intervention programmes and support being more broadly based. Australian mothers reported an eclectic use of resources and their engagement with services was according to their own choices and an understanding of different options, similar to the findings in a study conducted by Fitzpatrick et al. (2007). Australian mothers did not report feeling excluded by professionals as some mothers as reported by Tattersall & Young (2006). Australian mothers also demonstrated an ability to choose, drop or combine elements of early childhood intervention services as they required them. Even when mothers received a service from more than one agency, an important fact emerged. Mothers reported that they shared a particular relationship with one professional, which in essence, was similar to the positive experiences of mothers in the UK who enjoyed affirming working relationships with their peripatetic teacher of the deaf.

All the mothers wanted their children to learn to talk. However, three mothers in the UK suggested that the service they received was prescriptive in that it was same for all mothers and deaf children, thus there was little choice. As a result, their future decisions about signing or a cochlear implant were made more
difficult because of a rigid orientation towards one approach or another by the programme provided by the education department. In contrast, early intervention programmes in Australia were a matter of choice and whilst confirming Gregory’s (1995) assertion, having a choice of early intervention seemed not necessarily better than having no choice as in the UK.

Some Australian mothers said that having information early and realising the importance of early detection sharpened their resolve to make decisions quickly in order to maximise the opportunities provided by early detection (NHSP) or counteract the delays of a later diagnosis as in cases of non-NHSP mothers. Thus, again a notion of a timeline emerged from the diagnostic process to influence mothers’ agency. The findings revealed that the mothers of late diagnosed children enrolled in early intervention programmes sooner that the mothers with newborn babies. Interestingly, one mother said that if having a choice meant she had to “cold call” other mothers from a list of names or choose to visit programmes, then this type of choice was an unrealistic expectation for new mothers in the weeks following childbirth. As a consequence, some mothers delayed enrolling in an early intervention programme for several reasons until for example, after they had established a link with a cochlear implant team or established breastfeeding routines.

Australian mothers also said they were busy and two mothers talked about a feeling of being on a “roller coaster” following the diagnosis. Making a choice was time consuming for some and a difficult task for others, yet none complained of poor information. They quickly needed to become advocates for their child and mothers talked about “getting to know the system”, “the right person” or “being kept in the loop”, implying they needed to find their own ways into an intervention system. This suggests, either that the pathways were not clearly defined, or that there were many choices. It is also possible that some mothers were receiving adequate support through their clinical contacts and appointments, thus, what they were doing was enough.

Some mothers in all three cohorts described how they changed. They needed to absorb information about deafness quickly, in order to fulfill perceived changes to their own role to meet the changing needs of their child. These findings
contribute to what is already known about mothers’ early adjustment to deafness and what it means to integrate a deaf child into a hearing family (Calderon & Greenberg, 1999; Gregory, 1976). Mothers undoubtedly perceived their role to have changed as they said they were more likely to question what they were told and reluctant to accept advice; they regularly checked new information without waiting. For example, in the UK, the mothers found their own information about cochlear implants even when they were advised there was nothing else that could be done for their child or they refused to sign. In Australia, mothers changed programmes or Australian Hearing Centres to pursue their individual preferences for continuity, suitability or frequency of intervention programmes. The Australian mothers particularly, sensed that any further delays were detrimental to their child and they prepared for appointments in advance to re-position themselves as agents in this case, who know about their child rather taking the role of a patient who was expected to receive a prescription for the next treatment. Some mothers, in both the UK and Australia, sought second opinions. Contrary to Luterman and Kurtzer’s (1999) findings, none of the mothers in this study mentioned the support of other mothers.

Gravel and McCaughy (2004) argue that the critical times for the provision of support is between assessments, when new information needs to be addressed (e.g. when hearing aids were fitted) or decisions needed to be made (e.g. cochlear implant surgery). The literature suggests that mothers were most vulnerable at these times (Luterman, 1985; Luterman & Kurtzer-White, 1999; Roush, 2000). In this current study, this notion was exemplified by the practice of placing a peripatetic teacher with mothers of newly diagnosed children in the UK as final stage in the detection process. This reflects an eminent insight into the needs of mothers at this time and a particular quality of the public service early intervention provision in the UK (Kennedy et al., 2006). A teacher of the deaf often became a key relationship and a significant person in a mother’s future support network. In contrast, maintaining the theme of key relationships, some Australian mothers said they looked back to locate certain professionals who had offered support at critical stage, with whom they felt comfortable to talk about different issues after diagnosis.
The degree to which professionals were empathic and able to engage with mothers emerged as a critical factor in the development of maternal confidence. This exemplifies the importance of a person centred approach proposed by Harré (1972) rather than the cause and effect explanation, typical of clinical practice, where the ‘patient’ would follow rules of behaviour, either tacitly or explicitly, according to social convention. This resonates with a finding in a study conducted by Fitzpatrick et al. (2007), which revealed that parents’ access to services was extremely variable and effective support seemed to “be related more to the professional with whom the parent happened to be in contact than any characteristic of the health care services” (p.104). Similarly, in the current study this appeared to be of vital importance and relevant for the both cohorts of non-NHSP and NHSP mothers.

5.5 Conclusion

This research study has covered a period of nine years from 1999 – 2008. It focuses on a systematic review of the early detection of congenital hearing loss using the experiences of hearing mothers in the UK and Australia at a time of great change in programmes for early detection and intervention services. In this present study, the mothers told their stories of the diagnosis of deafness as an unexpected event. According to Crossley (2000a) a central tenet of phenomenological understanding is the challenge to human experience posed by the unexpected event. When mothers asked what congenital sensorineural deafness meant, they were exploring the experience in terms of its relationship and connection to something or someone else already within their understanding. Sarbin (1986) asserted that story telling is an organising structure for the flow of experiences and a way to account for one’s own activity that determine a sense of self. Moreover, Taylor (1989) argued that sources of self-understanding are only significant in the ways they matter to us, or are in-relation to us. For the mothers in this study, the diagnosis of permanent deafness, challenged the essence of their relationships with their babies as part of their being. Each mother could only draw on her previous activity represented by her own biographical and cultural connections.

As each story was told, similar themes emerged that gave coherence to the mother’s accounts. They talked about concern, asking for help, professional
responses to their requests and timing. As their stories unfolded, reassurance, delay and misplaced “wait and see” approaches did not conform to their expectation of a clinical response. Any sense of urgency, advanced by current health or developmental risk promotion, was seen only to permeate the practice of some exceptional professionals. Mothers did not detect a sense of urgency. In the case of non-NHSP mothers their own evidence overwhelmingly outweighed that of distraction test results or child nurse/family doctors’ observations. Mothers typically, became anxious and demanded a referral. If urgency was implicit in referrals after failed distraction tests, it did not translate into evidence in the mothers’ accounts. Rather, it was the mothers who wanted to avoid delay and sensed a need for exigency. Urgency became lost in referral systems, waiting lists and school term holidays and resonates with the “in-between” described by McCracken, Young and Tattersall (2008). “Wait and see” was a more likely response; it was a common theme borrowed from a narrow script of chronic otitis media management as a way of avoiding an over-referral of babies with false negatives distraction test results and minimising mothers’ concern.

Later, after diagnosis, systems moved more quickly for the UK mothers and hearing aids were fitted promptly and early intervention started with a peripatetic teacher visiting the home. In Australia, only when mothers needed to move between audiology service providers, cochlear implant teams/clinics and some agencies, did a sense of urgency reappear in the conversations they had with early audiological practitioners. Waiting emerged as a common theme here. Waiting for appointments and between assessments was stressful for mothers of newborn babies, whilst mothers in the non-NHSP cohort expressed regret and “panic” as they came to understand the full impact of the delay in diagnosis for speech and language development (Fitzpatrick, Graham et al., 2007). In Australia, after the implementation of NHSP at selected sites there seemed little evidence of a developmental or hearing checking system remaining for babies around seven or eight months of age. With the demise of the distraction test, this current study revealed that the system now relied on mothers to flag a concern about a hearing problem. Moreover, it was disturbing that despite the technological advances that enables newborns to leave hospital having had their hearing screened, Australian mothers’ experiences of
administrative systems, referrals and access to pathways for further testing and hearing aid fitting and were still highly variable.

Whilst many of the mothers’ experiences corroborate those of others in other studies, this current study reveals new findings that can contribute to the current literature relating to the practicalities of an early hearing loss detection process, professional communication and the preparation and training of practitioners coming to work in the field and they are summarised here.

- Maternal intuition about her child informed her concern about hearing. However, this seemed to have little value in gaining her entry to a diagnostic system irrespective of the age of the child or previous hearing screening or assessment history.
- In the UK, health visitors held a key role in mothers primary care network, however they failed to respond to mothers’ concern other than to offer hearing screens early thus ignoring the clear protocols for a successful test delivery.
- In Australia, mothers bypassed child health nurses in favour of a medical consultation with regard to their concern about hearing.
- Audiologists dealing with conductive hearing loss need to be more circumspect and aware of a child’s past history and a potential for sensorineural hearing loss.
- Mothers in the UK and Australia expected their babies’ hearing to be tested and understood the meaning of a screen test. They expected results and were confused by non-specific jargon and a ‘wait and see approach (non-NHSP).
- Reassurance was commonplace across all professionals; it was often misplaced and misused by professionals to invalidate maternal concern and privileged the professional view. Reassurance signalled a view that a hearing problem was non-urgent or of little consequence.
- Newborn hearing screeners drew on the same jargon that health visitors (UK) and child health nurses used in distraction testing to allay fears.
Mothers with concern were positioned as patients, which made asking the right questions difficult in a closed clinical encounter.

The hearing loss detection process was contextualised by a sense of time. Waiting was a recurrent theme for many of the mothers in either group. ‘Wait and see’ and ‘not urgent’ messages were contrary to the messages of urgency in the recent literature.

There are many steps in the process of identification, confirmation and early management of permanent hearing loss. What has emerged from this current research study is a need for service providers who can be unequivocally sensitive to the needs of all mothers, babies and young children and tailor information to suit their individual needs especially given the weight of current literature in favour of early detection, intervention and families’ engagement with services (Calderon & Naidu, 2000; Coplan, 1987; Davis & Hind, 2003; Joint Committee on Infant Hearing, 2007; Marschark, 1998; McCracken et al., 2008; Prieve & Stevens, 2000; Russ et al., 2004; Uus & Bamford, 2006; Vohr et al., 2008; Watkin et al., 2007; Young and Tattersall, 2005).

5.6 Limitations

The current study of the logic and ethics of medical screening has a number of limitations. The study, sensitive as it has been to the need to offer accounts, is limited to parents’ perceptions of their experiences of systems for hearing screening and diagnosis available to them at the time of the research. The study presents instances rather than samples to support its findings, which it is argued, are applicable rather than generalisable in other contexts. This study has attempted to draw attention to the impact of the often-competing professional grammars in the diagnostic discourse surrounding mothers of profoundly deaf children in two countries. The absence of voice of the professional in this study is a limitation that could be overcome by a researcher’s access to diagnostic case conference and parent/professional conversations in future studies. The study population was limited to those hearing mothers who self selected and their children who had a severe to profound hearing impairment and wore cochlear implants. Children who wore hearing aids, presented with additional needs, syndromal, adventitious or birth trauma induced deafness were excluded.
Chapter Six: Conclusion

The findings of this study confirm and synthesise other findings in relation to parental engagement in different facets of hearing loss identification and early management services. The significance of this study lies in its longitudinal design across systems’ time and place. The study undertook a systematic collection of mothers’ stories about their experiences and was undertaken at a time of change in technology for hearing screening; some babies were screened using a distraction test whilst others were identified using newborn screening techniques. There was a group of mothers in Australia with babies who fell between the old and new systems for hearing loss detection and these mothers found their own ways to a diagnosis by raising their concerns to either a child health nurse or a family doctor. The hope for this thesis was threefold. Firstly, that drawing on the mothers’ experiences would contribute to what is known about hearing mothers and how they adjust to their child’s severe or profound deafness. Secondly, that it would provide an insight into intervention practices, namely, the ways in which mothers receive the news of their child’s deafness, find information, make choices and become involved with early childhood specialist services. Finally, it would establish mothers as consumers of the system and further evaluation would be incomplete without the inclusion of their views.

The thesis takes an agential rather than a ‘patient’ centred view of a system. The early detection of sensorineural hearing loss appears to be a series of steps and stages marked by waiting and delay, inadequate professional communication and diverse levels of practitioner expertise and skill. Three arguments have been advanced. First, mothers’ concerns are an important factor in the identification of hearing loss and all mothers have inherent views about what constitutes a hearing problem. Second, the determination of hearing loss is clinically complex and cannot be easily confirmed through a single test result. Third, mothers need a range of information at different times, which is personalised, relevant to the event and of sufficient quality to embrace their perspectives and feelings about the problem.
As the literature reviewed indicates, none of these factors is original. The evidence in this thesis is particularly important because it is presented in the direct accounts of primary carers, the mothers. The results reveal that for all the mothers in this study, the diagnosis of permanent hearing loss was an unexpected event irrespective of the age of her child when it occurred. All the mothers were deeply shocked and anxious about their child’s future and this personalised the process; the level of shock was no less intense for mothers in either the non-NHSP or NHSP cohort. Rather than seeing the detection process as one clear pathway, mothers’ accounts revealed it to be a series of stages, where professional encounters were linked by referrals, each with their own institutional procedures and inherent delays. Importantly, the implicit urgency that has underpinned the rationale for early hearing loss detection in the last thirty years was incoherent with the tenor of some professional responses and institutional practices for babies and young children, especially when mothers raised the first concern.

This current study has shown that the system failed different mothers at different stages of the process. The evidence provided by their accounts points towards several contextual issues: professional communication, technical skill and fragile referral links, often disconnected from mother’s perceptions of the problem amidst diverse professional views that defined their practice. Failure in the system was not related to the validity or sensitivity of the screening or hearing tests, but to the human error associated with the ways in which test results were relied upon, interpreted and communicated to the mothers. A primary implication of this study is that new technology and automated test results are of little value alone without a clinical conversation which recognises a mother’s perspective of the nature of the problem, her concern and demonstrates practitioner skill and a need for sensitivity. Harré (2002) argues that the social objects, which this study has identified as fundamental to the deafness detection process, come to have meaning only through the conversational flow and social action between the agents. Mothers came to distraction screen testing with their own social objects, their interpretation of a startle reflex, a head turn or noise makers in their narrative of concern. The practitioner mediates different meanings, according to a detection discourse, and
these mothers’ experiences were of different clinical uses or interpretation of those objects. Newborn hearing screening offers new technologies for hearing testing where ear couplers, sensor sites and waveforms are the artifacts of the clinical practice, which afford congenital hearing loss identification. The phenomenological tradition directs attention to the relationship between the person and the object (Heidegger, 1962). Within the medical domain, new ways of seeing the world and its reliance on instruments, tools and technologies, puts the interpersonal and the joint construction of meaning at risk. The objects of diagnosis are shaped using linguistic forms and are “affordances” (Gibson, 1968; Harré, 2002). The narratives that I have relied upon here to explore discursive practice in the various social episodes of diagnosis have not only a research purpose but that this type of data could also serve a pedagogical purpose as case study material in the training of audiologists and early intervention practitioners. Thus the primary recommendation of this study is for the training of professionals in the field to include components that simultaneously sustain a focus on the agency and intentions of the practitioner as well as that of a mother without losing sight of the context and the affordances with which the practitioner mediates his or her meaning constructions.

A second recommendation relates to the medical context of early hearing detection systems and referral. It is threefold. Mothers’ preliminary encounters with professionals occurred in a variety of contexts representative of a community of practices where each context operates according to its own rules. Knowing what to do next was important for mothers. In the current study, especially in Australia, much confusion in institutional responses has been shown to exist between the mechanisms and practices of hearing screening, subsequent assessment procedures and the next stage, whether this was amplification (Australian Hearing), cochlear implant assessment (specialist hospital) or pre-existing specialist intervention programmes (home or centre based). The implication of this provides part one of this recommendation, for Australian mothers, that information about the next stage needs to be more clearly defined and the pathways, particularly for newborns, to be both seamless and cognisant of the day-to-day reality of caring for a baby or young child.
Part two of this recommendation concerns professional messages and the lack of acknowledgement of a mother’s concern. Harré and Secord (1972) argue that each person’s conduct is constrained by roles and pre-existing rules. The mothers’ positive perceptions of the skills of practitioners were measured by their sensibilities to their concerns and interest in understanding their personal perspectives. Surprisingly, few mothers who raised a concern about their child’s hearing experienced any degree of professional acknowledgement. “Wait and see” was a common outcome from an initial professional contact or preliminary hearing test, and mothers who waited received little information about what to expect, what to look for or what to do next. In retrospect, these mothers felt their concerns had been dismissed and they had been falsely reassured. Early dismissive or negative interactions caused mothers to feel resentful, particularly in regard to their own behavioural evidence that informed their view of the problem and their concern. They were frustrated and unhappy about the time wasted in arriving at a diagnosis, especially when they learned the true extent of their child’s hearing loss and the impact of a late diagnosis. The implication of these issues is that mothers became confused by some of the messages and mistrustful of professional advice or opinion. A second recommendation is to update and rationalise the professional talk concerning early hearing screening and detection routines to convey clear messages about the importance of hearing loss and remove the misplaced ‘wait and see’ jargon from audiologic practice in this context.

Part three relates to the cases of children already screened or those with otitis media. A complex mix of other factors often prevented an early identification of a sensorineural hearing loss. Yet it was a mother’s concern about her child’s development, despite medical management that emerged to challenge a predominant professional view of the problem. Further, for the mothers of babies screened at birth who later considered their child to have a hearing problem, it was more difficult to re-enter the system. These mothers had to wait until they could convince another professional to help them first before their children were diagnosed, often much later. This finding raises two key issues. First, the central importance for the ongoing need to monitor a child’s hearing and second, to appreciate the information a mother can bring to a medical
consultation about her child at any point. Whilst JCIH (2007) guidelines and the protocols in the UK refer to the need for ongoing monitoring of a child’s hearing status, no evidence emerged from the mothers’ stories of this safety net as common practice. Rather, throughout it was the energetic engagement of the mothers as they became aware of the constraints and shortfalls of diagnostic procedures (e.g. waiting lists, school holidays) together with the evidence of their child’s behaviour that they were able to realign their projects with others as they became aware of a timeline for speech and language development. A third recommendation is for a more transparent professional engagement with the monitoring of pre-school children hearing according to accepted protocols especially is the context of maternal concern.

The results suggest that the quality of mothers’ early relationships with professionals can significantly shape parents’ expectations of professional relationships overall. The question of professional skill, expertise and competence is multifaceted. Specifically, the results suggest that the skills of health visitors/child health nurses, audiologists and ear nose and throat specialists and their ability to engage with concerned mothers, babies and young children was sometimes inadequate. They fell short of recognising mothers’ individual differences and a common need to have their concerns acknowledged in sensitive ways. Health visitors/child health nurses were in a unique position to screen hearing and/or make a referral to audiology services based on a mother’s concern. However, Australian mothers, unlike mothers in the UK, appeared to have decided that a conversation about a hearing problem was beyond the scope of child health nurses and mostly they consulted their family doctors or went directly to a private Audiologist. A fourth recommendation, for Australian families is to clarify the entry points for health nurses or general practitioners with respect to mothers and children about whom they are concerned.

A fifth recommendation concerns the nature of the relationships with mothers for the duration of the process to detect deafness, the description of tests and testing protocols and the delivery of results. The contexts for mothers’ encounters with audiologists were varied and included ‘failed’ distraction test referrals (UK), ‘failed’ newborn screen referral (Australia), initial testing based
on a referral for maternal concern (Australia non-NHSP), retesting to confirm preliminary test results (all babies and children in the UK and Australia) and otitis media management (ENT referral). As a consequence, audiologists needed to be able to describe clearly the tests they were using, if they were going to be able to interpret and deliver results succinctly and in ways mothers could understand according to context of their child’s referral. This was not always the case. If mothers believed tests to be “routine” then results that identified a permanent hearing loss were unexpected and a shock. Mothers with children requiring further assessment were often given inadequate information about the purpose of repeat testing or the next battery of tests. Frequently, the time allocated for audiologic appointments and these types of conversations were inappropriate to meet individual needs. On the occasions, when audiologists worked in partnership or warned mothers in advance about what to expect and the time it would take, mothers responded positively saying they felt secure and unrushed. One system, which allowed the referring screener to go with the mother to her baby’s audiological assessment or another that provided a home visitor to talk with the family worked particularly well. These types of practice provided a timely link between the newborn hearing screening programme and audiology services and also sensitive support for the mother; they could be considered examples of exemplary practice.

Australian mothers’ experiences were very variable, yet it is not possible to ignore the evidence of mothers who talked about a person who they ‘knew’ or ‘trusted’ or ‘came with me’. This suggests mothers need support as they go through the audiologic assessment process, rather than just at the end. One of the major differences between the provision of early childhood intervention services in the UK and Australia was that in the UK, audiologic assessment, hearing aid fitting and early intervention services were integrated. Thus there was potential for continuity of professional support, e.g. the person who assisted with finalising the hearing testing and assessment was often the same person who first visited the mother at home. Consequently, in the framework of a national programme, some mothers acknowledged the skills of professionals on the one hand if they felt they had been able to explore options, whilst on the other, some felt constricted by the professional and the limitations of the
programme. Whilst this approach to intervention was not successful for all the UK mothers, for others it provided reliable and consistent support from the beginning. Australian mothers, as previously reported had to make choices about an early childhood intervention programme, which implied, by default, an early task of making a choice about communication. This took time for some mothers to choose a programme best suited to their needs as they considered all the information that they had been variously given by numerous professionals. It also highlights the importance of unbiased information. Conversely, although appearing seamless, the services in the UK, offered little or no choice in the way services were delivered. In Colorado, the CHIP program (Colorado Home Intervention Program) parents are supported by a single person (Colorado Hearing Resource Coordinator termed a CO-Hear) from the time a concern is raised until parents have established a connection with early management and/or support services. Given that not all birthing hospitals have screening programmes, the diverse entry points to services and choice in Australia, a fifth recommendation for Australian parents is for a similar trained person as the CHIP program to bridge the gap and support families during early hearing assessments, early auditory management and making choices about specialist children’s programs.

In Australia, not all the mothers took up early intervention options immediately after diagnosis, yet having options allowed mothers the freedom to change programmes when individual circumstances changed. From a service planning point of view and from this evidence, it is not possible to say if one way was better than the other. However it is clear that on the whole, for both groups of mothers they rated highly a consistent relationship with a professional that was broadly not in conflict with other information they were receiving at the time.

A sixth recommendation involves the disconnect experienced by Australian mothers between different testing routines, referral to different settings and conflicting information. Testing routines and referral issues were of particular relevance in Australia, where babies were referred simultaneously for cochlear implant pre-assessment and to Australian Hearing for hearing aid fitting. Some referrals completely failed mothers, e.g. after traveling great distances mothers were told that either their children were too old for testing, in the case of ABRs,
or that their children were unreliable or too difficult to test. Where otitis media “glue ear” was identified first, which often initially satisfied and resonated with a mother’s view of the problem, audiologists made little attempt to match and explore mothers’ perceptions in order to establish a joint point of departure for the next clinical conversation. Written information about what to do next had little relevance for most mothers in this first stage. A recommendation here is for a clear centralised system of follow up specific to early diagnosis from which to map a personal pathway for mothers so they can see 1) how the system unfolds and 2) make informed choices with a professional about the route they want to take.

For all mothers, their perception of a hearing problem was that it was a medical condition. Whether they wanted to raise a concern about a child’s hearing or be told about hearing loss conditions, knowing who to ask or what to do next were fundamental to mothers’ expectations of medical or child health practice. In writing these concluding statements, the nature of mothers’ responses to the unexpected event of permanent deafness, foreground powerful emotions about their responses to deafness, well documented in the literature, that cannot be ignored. Whilst hearing screening systems might claim to detect and diagnose hearing loss in babies in a few connected, timely steps, the experiences of the hearing mothers in this current study suggest that this clearly is not the case. Mothers’ grief about the loss of the child they expected or the one they knew, their despair about what to do next and their hopes for the future are an integral part of their diagnostic experience. In recounting mothers’ individual experiences of a diagnosis, this research study has exposed the complexity of each relational professional encounter and provided insight into the performance of professionals, especially in relation to their training, expertise and interpersonal communication. Apparatus and diagnostic tools may be thought to have superceded conversations with more definitive screening, computerized diagnostic testing and prescription, yet it is clear that a clinical conversation remains fundamental to the medical encounter and in particular a mother’s statement, “I don’t think my child can hear.”

The mothers’ stories, the data, are the social substance of qualitative research. Their accounts were generated from their encounters and interactions with
practitioners in a constantly changing technological environment. An important contribution to the field for this thesis is the disclosure of mothers’ insights and their need for genuine conversation and acceptance (Buber, 1966) to motivate a move away from models that view parents as separate from testing procedures. The linguistic analyses performed in this study have confirmed the need for professional relationships which are symbiotic, where the possibility exists to orient oneself within another’s position, and “understand their perspective as well as one’s own” (Howie, 1999). It is ontologically implausible and pragmatically indefensible that mothers’ agency and hearing loss detection systems are viewed as distinct structures. Moreover, from an ethogenic perspective, it is unworkable to isolate mothers’ social action from the context in which it occurs; positioning is a metaphor that restores understanding that moves beyond a causal research explanation.

This brings into relief the failure to distinguish heuristic from representational models, which as a consequence excludes mothers’ insights, to provide only a single impoverished view of the detection process. This study is a plea for the person of the mother and for a better understanding of mothers to encourage their inclusion as actors and principle stakeholders in future investigations into the efficacy of the newborn hearing screening systems. A final recommendation of this study is that any future evaluation of national hearing screening programmes needs to include the voice of the consumer, who provide a unique perspective, without which they cannot effectively be judged.
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References


Appendix A: Questionnaire

About this questionnaire.

I am a postgraduate student at the School of Education, University of Melbourne and also a parent of a profoundly deaf young man. I am particularly interested in babies and very young deaf children and their parents and learning more about the people who help families around the time of diagnosis of hearing loss.

As parents we constantly have to make choices on behalf of our children. Learning that a child has a hearing loss can be very confusing for parents if you are hearing yourself. Professionals can help you along the way with the many issues that need to be talked about particularly if you choose a cochlear implant for your child. I am interested in finding out more about you and your deaf child, your understanding of the impact of hearing impairment and the help you received at first.

I look forward receiving your completed questionnaire in the post paid envelop by the date below.

Friday 4th July 2008

For the purpose of data collection for this research project, your individual responses on the form will remain totally anonymous; you or your child or where you live cannot be identified in anyway. Your answers will be collated with those from other families so that I can see specifically what ‘parents’ say about support services for the hearing impaired, irrespective of where they live.

When you come to the end of the form and if you wish to contribute further to this research project then please sign the contact slip on the last page so I can contact you. This will also mean, you would like to be informed of the results of the survey

Only If you sign the contact form and give your contact phone number will a telephone call be made to you to confirm that you want to take part in the research.

A help line telephone number is available to you on the last page should you require further assistance filling out this survey
Appendix A: Questionnaire

Section 1: Background information about you and your family. About you:

Q1 Are you Male or Female?
   - o M
   - o F

Q2 Age
   - under 25
   - 25 -29
   - 30 -39
   - over 40

Q3 About your partner: Is he/she
   - under 25
   - 25 -29
   - 30 -39
   - over 40

Q4 About your family: How many children have you?
   - o 1
   - o 2
   - o 3
   - o 4
   - o more than 5

Q5 How many boys in your family?
   - o 1
   - o 2
   - o 3
   - o 4
   - o more than 5

Q6 How many girls in your family?
   - o 1
   - o 2
   - o 3
   - o 4
   - o more than 5

Q7 How many children under 3 years?
   - o 1
   - o 2
   - o 3

Q8 How many children are between 3 - 5 years?
   - o 1
   - o 2
   - o 3
   - o 4
   - o more than 5

Q9 How many children are over 5 years?
   - o 1
   - o 2
   - o 3
   - o 4
   - o more than 5
Q10 Who helps you with your child/children, either from your own or your partner’s family? Baby-sitting; going with you for shopping/appointments etc.

- partner
- your mothers or fathers
- your sisters or brothers
- your grandparents
- other __________________________________________

Q11 Outside your family, who helps you with your young children? (Not pre-school or school). You may tick more than one box

- your friends
- a baby-sitting group
- paid help/nanny/au pair
- crèche/child-care/minding (centre)
- we don’t use anyone

Q12 How many times a week does this occur?

- every day/all day
- every day/part day
- 4 days
- 3 days
- 2 days
- 1 day
- not regularly
- never

Section 2: Background information about your deaf or hearing impaired child:

Q13 Is your hearing impaired child a boy or a girl?

- M
- F

Q14 What age is he/she now?

- less than 12 months
- 13-24 mths
- 25-36 mths
- 37-48 mths
- 49-60 mths
- 5 years or more

Q15 What number is he/she in the family?

- 1st
- 2nd
- 3rd
- 4th
- 5th
- other
Q16  Who first suspected your baby might have a hearing loss?

- I/we never suspected
- GP
- A hearing screen tester
- Child Health Nurse
- You alone
- Audiologist
- Your partner
- Ear specialist doctor (ENT
- Child care worker/kindergarten teacher
- You & your partner together
- Other medical specialist
- Your parents
- Other Friend(s)
- Other _______________________

Q17  At what age did you first suspect there might be something different about your baby?

- I/we never suspected
- 0-3 mths
- 4-6 mths
- 7-12 mths
- 13-18 mths
- 19-24 mths
- 25-30 mths
- 31-36 mths
- over 3 yrs

Q18  Did your baby have his/her hearing screened before you left your birth hospital?

- yes
- no
- not sure

If the answer to Q18 was ‘yes’ please go to Q19, 20. If ‘no’ please go straight to Q 21, 22, 23.

Q19  [screen babies only]  Where did you go to next?

- local or base hospital in your town
- a city hospital
- a specialist baby audiology clinic (Australian Hearing; Community Health clinic etc.)
- an early intervention centre
- other ________________________________

Q20  [screen babies only]  How long did you wait?

- 1 week
- 2 weeks
- 3 weeks
- longer than a month
Q 21 [non screen babies only] If your baby was born at home or in a birth hospital that did **not** offer a hearing screen did you have your baby’s hearing screened after you left hospital?

- yes
- no

Q 22 [non screen babies only] Did you know about a hearing screening for newborn babies?

- yes
- no

Q 23 [non screen babies only] If your child was not diagnosed at birth, who told you that your child had a hearing problem?

- Audiologist told me/us after a hearing test
- Ear specialist doctor (ENT) told me/us
- GP told me/us
- Child Health Nurse told me/us
- Child care worker/kindergarten teacher
- Other

Q 24 [non screen babies only] Where did this happen?

- Local or Base hospital in your town
- City hospital
- Specialist baby audiology clinic (Australian Hearing; Community Health clinic etc.)
- Child care centre or kindergarten
- An early intervention centre
- Other

Q 25 [all babies] What age was your child diagnosed with a hearing loss?

- less than 4 weeks
- 5-6 weeks
- 7-12 weeks
- 4-6 mths
- 7-12 mths
- 13-18 mths
- 19-24 mths
- 25-36 mths
- over 3 yrs

Q 26 What level of hearing loss did you understand your child had?

- Mild
- mild/moderate
- Moderate
- moderate/severe
- severe
- severe/profound
- profound
- don’t know

Appendix A: Questionnaire
Q27  Can you remember what you thought this meant? You may tick more than one box.

- my child can’t hear my voice.
- my child can hear loud sounds.
- my child can hear some sounds.
- my child can hear some words.
- I don’t remember.
- other ________________________________

Q28  Can you remember which professional first spoke to you about your child’s hearing loss?

- audiologist
- teacher of the deaf
- ear specialist doctor (ENT)
- GP
- another member of the medical profession
- other ________________________________

Q29  When you were sure your child had a hearing loss what did you do next?

Q30  How did you hear about a service or program for hearing impaired babies or pre-school children in your region? You may tick more than one box.

- from an audiologist
- from Australian Hearing
- from an ear specialist doctor ENT
- from a infant health nurse
- from my GP
- from the education department
- from a teacher of the deaf
- from a friend
- internet
- Other ________________________________

Q31  How soon after finding out about your child’s deafness did you start your Early Intervention program

- 1 week
- 2 weeks
- 3 weeks
- 1 month
- 1-3 months
- 4-6 months
- 7-12 months
- longer
Q32 About your early intervention program: In the first few months how did you receive support to help you with the many issues to do with hearing loss, hearing aids and language development? You may tick **more than one box**.

- I attended a centre.
- I received home visits from a teacher of the deaf.
- I attended a centre and also received home visits.
- I went to special playgroup/kindergarten.
- I went to a school for the deaf.
- I received no special help
- I talked to other mothers/parents of deaf babies
- Other ________________________________

Q33 If you received a combination of help, home visits and centre based support Please say which you preferred.

- home visits
- visiting a centre
- liked combination

Section 3: Information about your deaf child and his/her hearing aids

Q34 How soon did your child receive his/her hearing aids after being diagnosed as hearing impaired?

- 1 week
- 2 weeks
- 3 weeks
- month
- more

Q35 Choose any of the following statements that best describe how you felt when your child received his/her hearing aids. Please tick **more than one box**

- I felt positive because he could now have a chance to hear me.
- I didn’t like the look of them at all.
- I disliked putting them in his/her ears.
- I was pleased that people would now see he had a problem.
- I was disappointed my child still could not hear me.
- I was relieved we had hearing aids at last.
- I felt alone with the problem.
- I didn’t know what to do.

Q36 How much time did your child spend wearing his/her hearing aids at first?

- not at all
- 1 hour
- 2 hours
- 1/2 day
- all day
Appendix A: Questionnaire

Q37 What were three things you noticed most that were different about your child after he/she started wearing his/her hearing aids?

1) ___________________________________________________________

2) ___________________________________________________________

3) ___________________________________________________________

Which professional, professional service or group were the most useful to you at this particular time following diagnosis? **Answer ALL the questions**, even if it doesn’t apply to you. Tick according to this code:
1 = Very useful; 2 = Some use; 3 = Not very useful; 4 = I did not experience this.

| Q38 Teacher for the deaf from an early intervention centre/program I attended | 1 | 2 | 3 | 4 |
| Q39 Visiting teacher from the education dept/EI centre in my home | o | o | o | o |
| Q40 Speech pathologist/therapist | o | o | o | o |
| Q41 Audiologist from a specialist hospital | o | o | o | o |
| Q42 Audiologist at Australian Hearing | o | o | o | o |
| Q43 A social worker | o | o | o | o |
| Q44 Other mothers/parents of deaf children | o | o | o | o |
| Q45 Parent support group, Parents Federation etc | o | o | o | o |
| Q46 Other (Please specify) |

*The next section is for parents of children with cochlear implants only*
Section 4: Information about you, your child and the cochlear implant.

Q47 When did you hear about a cochlear implant?
   - o Before my child was diagnosed with a hearing loss.
   - o At the time of diagnosis.
   - o At the time of hearing aid fitting.
   - o During the first 6 months of amplification.
   - o During the second 6 months of amplification.

Q48 Who told you?
   - o An audiologist at the hospital or hearing centre.
   - o A teacher of the deaf who visits me.
   - o My Early Intervention Program.
   - o Another mother/parent.
   - o An ear specialist. (ENT)
   - o My GP.
   - o A newspaper.
   - o A television program.
   - o other. ________________________________________

Q49 About the Implant Centre: How near was it to your home?
   - o 30 km  o 40 km  o 50 km  o 50 -100 km  o more then 100 km

Q50 When you first heard about implants, which of the seven statements closely describe what you felt about them. Please put them in order of the most significant for you, that means: WRITE 1 in the box by the statement that is the closest to your feelings at the time, then WRITE 2 in the next and so on.

   A It seemed much better than hearing aids  o
   B I wanted one very much for my child  o
   C Deafness wouldn’t be so much of a problem  o
   D I would give anything for my child to hear  o
   E I wouldn’t have to work so hard to get my child to hear  o
   F It would fix his/her hearing for good  o
   G I thought the surgery seemed frightening  o

Q51 Who helped you get information about a cochlear implant for your child?
   - o my teacher of the deaf.
   - o an audiologist.
   - o my early intervention program.
   - o my GP.
   - o my ear specialist (ENT)
   - o I got it for myself.
   - o Other
Section 5: Information about you, your child and your decision to have a cochlear implant.

Before you knew your child was suitable for a cochlear implant, can you remember how your child was going with his hearing aids? Again tick all the boxes that accurately represent what you thought at that time. Answer all the questions T = True: F = False; U = Undecided

Q52 He/she liked to wear them
Q53 He/she could hear some sounds
Q54 Hearing aids made little difference
Q55 He/she was using a lot of gestures
Q56 He/she was making some noises which sounded like words
Q57 He/she liked to play by himself
Q58 He/she could understand what I meant
Q59 He/she could understand what he/she wanted
Q60 Communication was difficult

Q61 Where did you receive most of your help for your child and his/her communication development at the time you were deciding about a cochlear implant and attending a cochlear pre-implant program at a hospital? You may tick more than one box.

- From an audiologist
- From my visiting teacher in my home
- From my Early Intervention Program
- From the implant team at the hospital
- From another mother/parent
- From an ear specialist (ENT)
- From my GP
- Other.

Section 6: Information about you and your child after you had made your decision to have a cochlear implant.

Q62 Please indicate which of the following statements was TRUE for you when you had made your decision. You may tick more than one box

- It was the hardest decision of my life
- I wanted my child to talk
- I don’t really remember making the decision
- I expected it to work better than hearing aids
- I felt the decision was out of my hands
- I knew it meant hard work
- I knew I wasn’t alone
- I’m glad deafness can be cured these days
- It was a long way to go to the implant clinic
Q63 Did the support teacher/therapist from your EI program go to the cochlear implant clinic with you?
   o yes  o no

Q64 How many visits did you make to an implant centre before you knew your child was a suitable candidate for an implant?
   o 1 visit  o 2 visits  o 3 visits  o 4 visits  o 5 visits  o more

Q65 What age was your child when you knew s/he was a suitable candidate for an implant?
   o less 3mths  o 4-6mths  o 7-9mths  o 10-12mths  o 13-15mths
   o 16-18mths  o more than 18mths  approx age

Q66 After you knew your child could have a cochlear implant, by that I mean he/she was a suitable candidate, you would have received much information from professionals about the speech or language development. How did you find this information?
   o confusing  o clear

Q67 If the answer to Q66 was confusing, please write down some of the things you found confusing
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

Q68 At the time of your child’s surgery how many professional people were you regularly seeing with your child altogether? Please include at the cochlear implant clinic, at your Early Intervention centre or appointments with people who visited you at home?
   o 2  o 3  o 4  o 5  o more

Q69 Whilst you were waiting for cochlear implant surgery what do you think was the most important part of your job in helping your child learn to talk? Write down the three things that you remember doing with your child that you felt were really valuable.
   1
   ____________________________________________________________
   2
   ____________________________________________________________
   3
   ____________________________________________________________
Q70 Have these important things changed now that your child is implanted?

 o Yes o No o Undecided

If the answer to the last question was Yes: write down what you now think is important for you to do.
If the answer was No: Write same on all three lines.
If the answer was undecided then leave the space blank.

1__________________________________________________________

2__________________________________________________________

3__________________________________________________________

This is the end of the questionnaire
Requests for support or help with filling in this form can be made by telephone to:

A/Prof Margaret Brown    03 8344 0987
Alison M Marchbank        03 8344 0970 wk    Mob 0417361065
                             03 95647248  hm

NOW —

PLEASE GO TO THE NEXT PAGE TO SIGN THIS SURVEY
Thank you for your assistance in filling in this questionnaire, your comments are greatly valued and very helpful.

Please be free to write any further comments about the content of this survey BELOW or on the back of the form.

I/we want the researcher to call and tell me/us more about the study.

Signature____________________________

Date ____________ Tel numbers: _(____)_____________

A good time to call is  Day_____ am ___/'__ pm

PLEASE RETURN THIS FORM TO (in the envelop provided)

Melbourne Graduate School of Education
PO Box 634
CARNEGIE
Vic 3163

Appendix A: Questionnaire
Appendix B: Recruitment Letters

B1  Co-ordinators of cochlear implant programmes (UK)

Dear Programme Co-ordinator

I am writing to inform you about my master’s research project which is to be undertaken this year in the School of Education at the University of Exeter. The study is designed to gain a better understanding of parents’ perceptions of professional support when they suspect and subsequently discover their child’s permanent severe hearing loss and their experiences when they choose a cochlear implant as a listening device. For the purpose of the study I need to identify families who wish to participate. You have indicated that you would be willing to first, review my questionnaire pack and secondly, to distribute on my behalf according to families registered with you who have children wearing a cochlear implant and who are younger than seven years of age. An outcome of the study is expected to enhance our understanding of professional intervention practice following the diagnosis of severe sensori-neural hearing loss and parents’ decisions with respect to cochlear implant surgery.

Programme co-ordinators who agree to mail out the questionnaire pack will not be asked to select families or engage with families at a personal level. The task will simply be to distribute the packs in order that families are aware of the project and can choose to become involved with the research. Families are offered two levels of response 1) returning a completed questionnaire, and 2) returning a completed questionnaire with a signed request for further involvement.

I look forward to your involvement with my research study and I have enclosed a questionnaire pack for your perusal. If you have any questions or which to discuss the study in more detail before making your decision do not hesitate to call me on the contact numbers below.

Yours sincerely

Alison M Marchbank
Dear Service provider

I am writing to inform you about a new research project I am undertaking for my PhD thesis in the School of Education at the University of Melbourne. The study is designed to gain a deeper understanding of parents’ perceptions of the support they receive before and after their baby or young child has been diagnosed with hearing loss. The addition of universal newborn hearing screening into the detection protocols for the early identification of hearing impairment, has meant that many programs for the support of families with deaf pre-schoolers have needed to be revised or adjusted to include parents with very young babies. In a preliminary study, conducted in the United Kingdom in 2000, before newborn hearing screening became available, findings revealed that many parents had difficulty in finding appropriate clinical advice, family support and programs for their children’s speech and language development, especially when they suspected their own child’s hearing problem over a period of time.

In developing a second study and in the context of neonatal hearing screening we would like to enlist your help to identify families who might wish to participate in this research. This will involve your distributing a questionnaire to all families currently enrolled in your program. Centres that choose to distribute the questionnaire and the respondent families to the study will be remain totally anonymous and will not be able to be recognised. On completion of the thesis, the findings presented as an overview, will be circulated to all the participating agencies and every family who requests it. Outcomes from the study are expected to increase our understanding of what parents want from an early intervention program to inform current practice.

If you chose to be distribution agents for this research study what will it involve?

- Your role in supporting this research will be to mail out the questionnaire packs to all families enrolled in your program. No pre-selection of respondents is necessary to ensure that families are free of influence from their caseworkers, program managers and early intervention agency. You will not be asked to collect or collate replies, give information or remind parents to engage with the research project. Distribution will be a single administrative task at no cost to you.

- If you accept you can nominate a person, preferably someone not directly involved with clients to be responsible for the mail out of the packs. This person will be fully briefed with respect to the research protocols. The briefing will include issues relating to non-English speaking families and/or those parents who present with literacy or medical support issues. The research team will manage the returns and any enquiries for support or information, which will be available to all families by telephone.

Families have two levels of response 1) returning a completed questionnaire, and 2) returning a completed questionnaire with a signed request for further involvement.
We look forward to your favourable response to this request and have pleasure in submitting a questionnaire pack and plain language statement for your perusal. If you have any questions or want to talk about the project further, before making your decisions then please feel free to call the contact numbers below.

Yours sincerely

Alison M Marchbank

Candidate PhD, B.Ed. (Melb.) Post Grad. Dip. Special Education (HI) (Victoria College); Dip.Teach. (NZ). Cert. Ed. (UK)
B3  Plain Language Statement to parents

Parents’ perceptions of support before and after the diagnosis of hearing loss in young children.

Dear Parent(s)

You are invited to participate in the above research project, which is being conducted by Dr. P. Margaret Brown and Ms Alison Marchbank (PhD student) of the Department of Education at The University of Melbourne. Alison Marchbank is an experienced teacher of the deaf and has been involved in early intervention for many years. She is also a parent. The project will form part of Ms Marchbank’s doctoral study and has been approved by the Human Research Ethics Committee.

The aim of this study is to explore the perceptions of parents of the professional support and intervention they received during the process to (1) diagnose their child’s hearing loss and (2) determine hearing levels and the use of hearing aids or eligibility for a cochlear implant. Parents routinely have to make choices for their children and this is particularly true when severe/profound hearing loss is detected early in a child’s life and babies need hearing aids or a cochlear implant as a preferred listening device option. The data collected during this study will contribute to the development of best practice in the support of families during the diagnosis of deafness and inform early intervention services for parents of deaf and hearing impaired pre-school children who choose a cochlear implant.

Participation in this project is completely voluntary. All parents of deaf and hearing-impaired children enrolled in your early intervention centre have received this letter, and we have no way of knowing whether your child is a hearing aid wearer or a cochlear implant user. There are two ways you can take part in this study:

1. Complete and return the questionnaire that is attached to this letter using the prepaid envelop. This may take about 30-40 minutes. This will provide information about your family, your child’s hearing loss and the people who helped you.
2. You can choose whether or not to take further part by attaching your contact details when returning the questionnaire to the university.

If you reply with your contact details then the student researcher will contact you to arrange an interview time to talk further about your responses and experiences during the diagnosis of hearing loss, learning to wear hearing aids and/or your decision to have your child implanted. All parents who are willing to be interviewed will be asked questions about what they wrote on their forms and their responses will be recorded using an audiotape recorder to ensure an accurate record of what you say. This will take approximately 60 minutes. After the interview and if you wish we can provide you with a transcript of the interview conversation. We will remove any references to personal information that might allow someone to guess your identity, where you live or the location of your program or medical centre.

Plain Language Statement
Parents perceptions of support during the diagnosis of hearing loss in young children
HREC no: 0721963.1 25-Feb-08

Faculty of Education
The University of Melbourne, Victoria 3010 Australia
T: +61 3 8344 8285  F: +61 3 8344 8529  W: www.edfac.unimelb.edu.au

Appendix B: Recruitment Letters
This research project does not require any information about the names of organisations, agencies, medical centres and/or specific people who have helped or supported you since you found out your child was deaf. In this way you can be sure that you cannot be identified from this study and that what you say is anonymous. We treat your information confidentially. The researchers will provide a contact number for parents who wish to change or withdraw information they give at any stage. Once the thesis arising from this research has been completed, participants who added their contact details will be notified and you can ask for a brief summary of the findings from the School of Education. The data collected for the purpose of this research will be kept locked for five (5) years, after which it will be destroyed.

Information given by parents is always of great value and we look forward to receiving your completed questionnaires and where possible having an opportunity to discuss your experiences in more detail.

Alison M Marchbank, PhD Cand.

Should you require any further information, or have any concerns about the conduct of this research, please do not hesitate to contact:

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<th>Name</th>
<th>tel</th>
<th>mob</th>
<th>email</th>
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<tbody>
<tr>
<td>Alison Marchbank</td>
<td>03 8344 0970</td>
<td>0417361065</td>
<td><a href="mailto:a.marchbank@cpord.unimelb.edu.au">a.marchbank@cpord.unimelb.edu.au</a></td>
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<tr>
<td>Dr P Margaret Brown</td>
<td>03 8344 0987</td>
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<td><a href="mailto:p.m.brown@unimelb.edu.au">p.m.brown@unimelb.edu.au</a></td>
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Plain Language Statement
Parents perceptions of support during the diagnosis of hearing loss in young children
HREC no: 072136.1 25-Feb-08

Appendix B: Recruitment Letters
Appendix C: Examples of Thematic Coding (IPA)

Appendix C: Examples of Thematic Coding (IPA)
252

Appendix D: Themes relating to concern, testing
and outcomes for mothers in the UK and
Australia [non-NHSP cohorts]

Appendix D: Themes relating to concern, testing and outcomes for mothers in the UK and Australia
[non-NHSP cohorts]


Appendix E: Themes relating to mothers' actions after diagnosis

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Appendix E: Themes relating to mothers' actions after diagnosis
Appendix F1: Themes relating to mothers' observations after hearing aid fitting [UK]

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<th>Statement 3</th>
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<td>1</td>
<td>Nothing</td>
<td>HA difficult to fit</td>
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</tr>
<tr>
<td>2</td>
<td>Nothing</td>
<td>HA useless</td>
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<td>3</td>
<td>Liked them for a short while</td>
<td>Some response to noises</td>
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<td>4</td>
<td>Nothing</td>
<td>Very frustrated</td>
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<td>No change</td>
<td>Some startles</td>
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<td>6</td>
<td>No change</td>
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<td>7</td>
<td>Turned to my voice</td>
<td></td>
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<tr>
<td>8</td>
<td>Went quiet</td>
<td>Pulled HAs out</td>
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<td>9</td>
<td>No change</td>
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<tr>
<td>10</td>
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<tr>
<td>11</td>
<td>Wouldn't wear HA</td>
<td>Battled to put HA in</td>
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<td>12</td>
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<td>Responded to Dad's voice</td>
<td>Seemed quiet</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>No change</td>
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<td>15</td>
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<td>HAs fell apart all the time</td>
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<tr>
<td>16</td>
<td>No difference</td>
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<td>behaviour was improved</td>
<td>Seemed happy</td>
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<td>19</td>
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<td>Pulled HAs out</td>
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<tr>
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<td>Disliked HAs</td>
<td>Wouldn't wear HA</td>
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<td>21</td>
<td>More vocal</td>
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<td>22</td>
<td>Watched TV more</td>
<td>Looked at my face</td>
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<tr>
<td>23</td>
<td>No difference</td>
<td></td>
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<td>24</td>
<td>Wouldn't wear HA</td>
<td>Pulled HA apart</td>
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<td>Responded to some sounds</td>
<td>Started to vocalise</td>
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<td>27</td>
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<td>Nothing much</td>
<td>Pulled out HA</td>
<td>No auditory response</td>
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<td>29</td>
<td>HA Feedback stopped him hearing anything</td>
<td>Observed auditory response</td>
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<tr>
<td>30</td>
<td>Didn't notice much</td>
<td>HAs whistled all the time</td>
<td>Change in behaviour</td>
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<tr>
<td>31</td>
<td>Nothing</td>
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<td>Negative behaviour/comment</td>
</tr>
<tr>
<td>32</td>
<td>My child did not like HA</td>
<td>Went quiet</td>
<td>HAs removed/refused to wear</td>
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<td>33</td>
<td>Could hear TV</td>
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<td>Vocalisation</td>
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<td>Nothing changed</td>
<td>Behaviour got worse</td>
<td>HAs feedback/negative comment</td>
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<td>Seemed to attend to face more</td>
<td>Didn't like to be left alone</td>
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<td>Nothing</td>
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<td>Could hear music</td>
<td>Didn't like me putting HAs in</td>
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<td>38</td>
<td>Looked more 'with it'</td>
<td>Still didn't talk</td>
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Key:
- No auditory response
- Observed auditory response
- Change in behaviour
- Negative behaviour/comment
- Vocalisation
- HAs feedback/negative comment
- Other
### Appendix F2: Themes relating to mothers' observations after hearing aid fitting [Australia]

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<td>Response to human voice</td>
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<td>Turned to sound</td>
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<td>Nothing</td>
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<tr>
<td>16</td>
<td>What was in front of her</td>
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<td>18</td>
<td>More social with others</td>
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<td>20</td>
<td>Responded to laughter</td>
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<td>22</td>
<td>Attention improved</td>
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<td>Nothing</td>
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<tr>
<td>33</td>
<td>More alert</td>
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<td>43</td>
<td>Overwhelmed by noise</td>
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<td>Overwhelmed due to loud</td>
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<td>Nothing</td>
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<td>Locating sound</td>
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<td>Turning to sound</td>
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<td>Less emotional/more stable</td>
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<td>Lack of reaction</td>
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<td>Pulled them out</td>
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<td>86</td>
<td>Didn't notice much</td>
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<td>90</td>
<td>Didn't like HA</td>
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<td>92</td>
<td>Could hear loud sounds</td>
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<td>He was happier</td>
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<td>Became more interested in speech</td>
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<td>Cuddles hurt his ears</td>
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<td>Needed to enjoy music</td>
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<td>Big difference</td>
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### NHSP

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<td>25</td>
<td>Started to listen</td>
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<td>36</td>
<td>Lots of feedback</td>
<td>Appeared to make a difference</td>
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<td>Lacked different</td>
<td>Nothing</td>
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<td>66</td>
<td>Aware of sound</td>
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<td>68</td>
<td>HA's made no difference</td>
<td>No change</td>
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<td>Nothing</td>
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<td>Nothing</td>
<td>No benefit from HA</td>
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<td>No difference</td>
<td>HA removed/refused to wear</td>
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<td>100</td>
<td>More responsive</td>
<td>Voice quality changed</td>
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<td>Nothing</td>
<td>Feedback was a major problem</td>
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<td>More interested in environment</td>
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<td>148</td>
<td>Language started</td>
<td>Behaviour improved</td>
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**Key**

- **No auditory response**
- **Observed auditory response**
- **Change in behaviour**
- **Negative behaviour**
- **Vocalisation**
- **HA feedback/negative comment**
- **Other**
Author/s: Marchbank, Alison M.

Title: Hearing mother’s inceptions and perceptions of systems to detect congenital hearing loss in their infants and young children prior to the fitting of a cochlear implant

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