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A Qualitative Analysis of Parental Coping with an Early Diagnosis of Hearing Loss in Ireland

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A thesis submitted to the National University of Ireland in fulfilment of the requirement for the degree of Doctor of Philosophy

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Abstract

The recent implementation of Universal Neonatal Hearing Screening (UNHS) in all 19 maternity hospitals across Ireland has precipitated early identification of paediatric hearing loss in an Irish context. This qualitative, grounded theory study centres on the issue of parental coping as families receive and respond to (what is typically) an unexpected diagnosis of hearing loss in their newborn baby. Parental wellbeing is of particular concern as the diagnosis occurs in the context of recovery from birth and at a time when the parent-child relationship is being established. As the vast majority of children with a hearing loss are born into hearing families with no prior history of deafness, parents generally have had little exposure to childhood hearing loss and often experience acute emotional vulnerability as they respond to the diagnosis. The researcher conducted in-depth interviews primarily with parents (and to a lesser extent with professionals), as well as a follow-up postal questionnaire for parents. Through a grounded theory analysis of data, the researcher subsequently fashioned a four-stage model depicting the parental journey of receiving and coping with a diagnosis. The four stages (entitled Anticipating, Confirming, Adjusting and Normalising) are differentiated by the chronology of service intervention and defined by the overarching parental experience. Far from representing a homogenous trajectory, this four-stage model is multifaceted and captures a wide diversity of parental experiences ranging from acute distress to resilient hopefulness.

Acknowledgments

Firstly, I would like to sincerely thank the parents and professionals who participated in this research. Their sincere desire to affect positive change by contributing to this study was exemplary, their honesty and openness in interviews was moving, and their selfless dedication to (their) children with hearing loss was inspiring.

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Towards the end of this study Robert jested that I was expecting twins, a baby and a thesis. The impending arrival of my baby, Fionn, was my greatest motivation to finish this thesis on time. Fionn remains entirely oblivious to his twin, and I remain entirely smitten by Fionn.

My husband, Peter Kenny, has been my constant companion from beginning to end of this research. From the outset he proofread my application form, drove me to my interview, debriefed with me afterwards, and rejoiced with me when I was offered this study. Over the past three years he has listened patiently to every meticulous detail, agonised with me over every challenge, prayed for me during every hurdle, and rejoiced with me during every resolution. He has proofread every draft of every chapter with attentive care, introducing me to grammatical revelations such as the oxford comma! He has made me countless cups of tea during early morning and late night working hours. His understated manner, his consistent support, his unassuming wisdom, his selfless love, has become all the more evident to me throughout this study.

Declaration

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which has been accepted for the award of any other degree or diploma of a university or other institute of higher learning, except where due acknowledgement is made in the text.

Signed_____ Date_____

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Acronyms used in this Study

ABBR	Automated Auditory Brainstem Response
AOAE	Automated Otoacoustic Emission
CA	Citation Analysis
CREC	Clinical Research Ethics Committee
ENT	Ear, Nose, Throat (Specialist)
GT	Grounded Theory
HIQUA	Health Information and Quality Authority
HSE	Health Service Executive
NARG	National Audiology Review Group
NCR	No Clear Response
PCHI	Permanent Childhood Hearing Impairment
UNHS	Universal Neonatal Hearing Screening

Prologue: Personal Reflection

Before this study was even conceived of I had a specific eureka experience regarding research. As a newly qualified social worker, I was unexpectedly requested to undertake an audit of supported accommodation for vulnerable adults in the community. This endeavour occurred in the context of the Health Information and Quality Authority's (HIQUA) assessment of residential units for vulnerable members of society (including elderly people, adults with intellectual disabilities, psychiatric patients etc.). My acquiescence was reluctant to say the least: at the time I was finding my feet in my new role and felt swamped with the volume of my own work. The prospect of undertaking this lengthy audit on top of my already demanding schedule was overwhelming. However, I reluctantly agreed.

In the coming weeks my reticence was not only dissipated but transformed into gratitude. I remember sitting at the table of one of the newly-established residential homes as the staff explained the circumstances that necessitated this new unit. I learned that the middle-to-late aged adults with intellectual disabilities living there had actually spent the vast majority of their lives in a psychiatric institution despite not having a psychiatric illness. For decades they were inappropriately medicated, mistreated, and institutionalised. They would still be confined within the four walls of the institution with no quality of life, except for a HIQUA evaluation that had occurred only a few years previously. This evaluation identified the inappropriate placement of these adults, the unacceptable conditions of their habitation, and precipitated their removal into community care. As I assessed the new lease of life that these resilient adults now enjoyed, I was struck that this dramatic change was instigated by research.

I had previously undertaken a number of research projects as a university student, however this was the first time I fully appreciated the extraordinary impact of ordinary research. As I've reflected on this revelation over the past number of years, I've come to

recognise that it is not one research study in isolation that progresses change. The HIQUA evaluation emerged out of a context of a greater body of research. It is the culmination of studies that alters the climate. That conviction has never left me.

This revelation of the importance of research has permeated my approach to this study. When the prospect of this study arose I recalled the above experience in the interview room, recounting its significance. As I was offered, and accepted, the opportunity to undertake this study, I felt the great privilege of this commission. While interviewing participants I have been struck by their selfless commitment, not only to their children, but also in their earnest desire to improve the health-care system for other families. When writing up the findings of this study I felt the weight of responsibility to do justice to the important issues raised. As I fashioned recommendations, I have been driven to genuinely seek positive change rather than dispatch empty proposals. And so this study is much more than a means to an accredited end, it is full of personal investment and conviction.

I began this study with a great interest, but little knowledge of the issues facing families who receive an unexpected diagnosis of their baby's hearing loss. I now come to the end of this study, not only immersed in the magnitude of the subject, but now as an expectant parent myself, feeling the awakening of new life within me. As I eagerly anticipate the day I have the indescribable joy of holding my own newborn baby in my arms, I've asked myself how I would react if I too were faced with an unexpected diagnosis. Placing myself in the shoes of the parents I encountered during this research has deepened my empathy and respect for them.

This study represents the most challenging and fulfilling undertaking of my academic career. During its composition, I often reflected on the practice of the classical composer Johann Sebastian Bach who habitually inscribed the three initials SDG at the end of his manuscripts (an acronym for *Sola Dei Gloria).* And so as I present this thesis, I inscribe SDG with the aspiration that my work would sing the same praise.

1. Introduction

1.1 Introduction: The Context of this Study

This study was not fashioned in a vacuum. It emerged from the context of dynamic changes within the paediatric audiology services in Ireland. These changes were initiated in June 2009 when Laverne McGuinness (the National Director, Integrated Services Directorate of the Health Services Executive) requested and commissioned a national review of the Irish audiology services (NARG, 2011). A team of 23 evaluators (consisting of 1 service user and 22 professionals) were selected from a variety of disciplines including audiology, speech and language therapy, administration, ENT, public health medicine and nursing, management, and teaching for deaf[1] children etc. (NARG, 2011). These individuals formed the National Audiology Review Group (NARG) which was chaired by Professor John Bamford, the honorary professor of audiology in the University of Manchester. The NARG was instigated in September 2009, and subsequently met a total of 12 times over the following 14 months (NARG, 2011). In 2011, after a two year evaluation process, they published what became known as the NARG Report, which provided a critical assessment of the audiology services in Ireland. This Report, as well as the subsequent changes it incurred, forms the bedrock of this study.

1.2 The National Audiology Review Group (NARG) Report

The NARG Report represents the "most extensive examination to date of audiology services in Ireland" (NARG, 2011, p.12). The opening chapter of the Report affirmed that "there are many committed and dedicated professionals" who "should be praised for their

[1] The researcher is adopting the same distinction as Young et al who specify that "the convention using upper case `Deaf' will be followed when referring to the cultural-linguistic phenomenon, and lower case `deaf' when referring to the audiological condition" (Young, 1999, p.157-158). To ensure consistency in this study, the researcher will employ the lower-case "deaf "as the default term, unless the reference to a cultural-identity is explicit. Furthermore, the researcher will not edit the use of the terms in direct quotations from literature.

efforts" (NARG, 2011, p.12). However, within same sentence these admirable practitioners were depicted as struggling "to deliver good quality services under challenging circumstances" (NARG, 2011, p.12).

The ensuing chapters of the NARG Report uncovered these "challenging circumstances" in detail, highlighting the serious deficits in the Irish audiology services (NARG, 2011, p.12). In particular the absence of Universal Newborn Hearing Screening (UNHS) in maternity hospitals across Ireland was strongly criticised. Without newborn screening, the NARG Report documented that the average age of a child's first referral for diagnostic testing was either 11.3 months (for severe/profound hearing loss) or 18.7 months (for moderate hearing loss), resulting in an "unacceptably late" diagnosis of childhood hearing loss (2011, p.46, 119). In addition, this late identification of hearing loss was further compounded by the reality of late intervention. In one particular region the average age of initial intervention for children was either 24 months (for severe/profound hearing loss) or 60 months (for moderate hearing loss) (NARG, 2011, p.15). The comparison of these statistics with international standards, substantiated the conclusion that the timeframes within the Irish audiology services were unacceptable (NARG, 2011). For example the USA have a 1-3-6 strategy, indicating that every child should be universally screened for hearing loss no later than one month after birth, receive a diagnosis by three months, and be enrolled in an early-intervention programme by six months (Gaffney et al, 2014).

The NARG Report stressed that this combination of a late diagnosis and late intervention in Ireland, has a detrimental impact upon the lives of children (NARG, 2011). Delayed access to sound at critical developmental stages, adversely impacts the child's acquisition of language causing them to fall behind age appropriate communication milestones. This can "severely disrupt" educational, social, emotional and psychological development particularly as the child reaches school-going age (NARG, 2011, p.28). Ultimately, this

engenders long term consequences for the child, family and society, impacting "employment, social inclusion and quality of life" and also propagates "long-term costs associated with special education and support" (NARG, 2011, p.28) The NARG Report stressed the severity of these consequences which parents described as "crippling" (NARG, 2011, p.59).

As well as the serious implications for the outcome of the child, the NARG report also highlighted the acute distress caused to parents. The Report documented many parents' ongoing frustrations and grievances as they struggle with the day-to-day reality of a late diagnosis and late intervention:

> Why did it take so long for this diagnosis to be made? My child … is at a constant disadvantage because of [*sic*] her hearing age is over two years less than her chronological age, her speech intelligibility is inferior to her peers which leads to frustration and isolation and she is not even six years old yet! We are continuously trying to catch-up for the missing hearing years with speech therapy, special needs assistants, resource teaching hours, and I have reduced my working hours to the bear [*sic*] minimum in a bid to do extra-curricular work to ensure that she doesn't regress because of the late diagnosis (NARG, 2011, p.59).

Importantly, the NARG Report recorded the parental criticism that "the lack of availability of infant screening, as a matter of course, is an absolute disgrace and a failing on the part of our health services" (NARG, 2011, p.59).

Drawing upon international research (including publications of the Institute of Hearing Research), and good practice principles (particularly from a UK context), the NARG Report (2011) urgently recommended the introduction of UNHS in Ireland. With an early identification of hearing loss, and subsequent early intervention, the Report argued that rather than having to endlessly "catch up", children receive the opportunity to enter school with "age-appropriate language", and to develop educationally, socially, and emotionally at the same "trajectory" as their peers (NARG, 2011, p.57, 58). Thus, with an early diagnosis the outcome for the child is dramatically improved (NARG, 2011).

As well as recommending early identification of hearing loss, the NARG Report stressed that this needs to be accompanied by timely and quality intervention (2011). It detailed numerous difficulties with the (then) current system which compromised the efficacy of the services provided to children. In particular, the following issues were highlighted (NARG, 2011):

- Ambiguous care-pathways for families with poor access to services
- Lack of multi-disciplinary collaboration
- Insufficient information provided to families and poor communication
- Inappropriately long waiting times for appointments and equipment
- Inferior quality of equipment, as well as poor facilities and infrastructure
- Lack of repair services
- Lack of resources and training, as well as staff-shortages
- Poor coordination of services, incurring duplication, fragmentation, and lack of leadership
- Geographical inconsistency between services with no national dataset to monitor activity and ensure consistency
- Dearth of standardised policies and procedures

The NARG Report concluded that many of the services provided to families were "substandard" (NARG, 2011, p.14).

1.3 The Introduction of Universal Neonatal Hearing Screening (UNHS)

The NARG Report (2011) proved to be a seminal publication which precipitated the widespread introduction of UNHS in Ireland. In April 2011 the first UNHS programme arising

from the NARG Report[2] was piloted in Cork University Maternity Hospital (CUMH), Ireland (HSE, 2012). Significantly, this pilot programme, and the proposed national implementation of UNHS, was commended by many professionals working in charity organisations and clinical positions within the HSE, who had long advocated for its implementation. Many of these individuals eagerly welcomed the recommendations outlined in the NARG Report and supported the implementation of UNHS enthusiastically.

Although the implementation of this initial pilot programme signified a positive and innovate development in Ireland, UNHS had already featured in international health care standards for decades. Indeed the screening has not only been implemented but also endorsed in USA legislation since 1999 (when the *Newborn Infant Hearing Screening and Intervention Act* was signed into law) which served to precipitate national coverage (Young & Tattersall, 2005). Likewise, following its introduction in the UK health care system in 2001, it reached national coverage by 2006 (Young & Tattersall, 2005). Within an Irish context, Professor Bamford (who spearheaded the NARG) acknowledged that the availability of a pilot UNHS programme in Cork University Maternity Hospital is in "an encouraging start, but we can only be satisfied when all births are covered" (Condon, 2011, p.1).

1.4 National Implementation

At the genesis of this study (October 2012) UNHS was a very recent phenomenon in the Irish health care system. The national implementation of the programme across all 19 maternity hospitals in Ireland has occurred in increments throughout the composition of this study. The following table tracks this progression.

[2] Two Irish hospitals (Galway University Hospital and Mayo General Hospital) already had a pre-existing newborn hearing screening programme in operation since the year 2000 (Adelola, et al., 2010). These programmes were later incorporated into the national UNHS programme recommended by the NARG Report (see Table 1.1).

Table 1.1 The Implementation of UNHS across Maternity Hospitals in Ireland[3]

Date:	Hospital:
By April 2011	○ Cork University Maternity Hospital
By November 2011	○ Waterford Regional Hospital ○ Wexford General Hospital ○ Kerry General Hospital
By March 2012	○ South Tipperary General Hospital ○ St. Luke's General Hospital in Carlow-Kilkenny
By January 2013	○ Midland Regional Hospital, Mullingar ○ Midland Regional Hospital, Portlaoise ○ The Rotunda Hospital, Dublin ○ The Coombe Women & Infants University Hospital, Dublin ○ Our Lady of Lourdes, Drogheda ○ The National Maternity Hospital, Holles Street, Dublin ○ Cavan General Hospital
By April 2013	○ Letterkenny General Hospital ○ Sligo Regional Hospital
By July 2013	○ Galway University Hospital (a pre-existing newborn hearing programme had previously been in effect since the year 2000)
By August 2013	○ Portiuncula Hospital, Ballinasloe, County Galway
By September 2013	○ Mayo General Hospital, Castlebar (a pre-existing newborn hearing programme had previously been in effect since the year 2000)
By November 2013	○ University Maternity Hospital, Limerick

[3] Table compiled by the Researcher, accessing information from a number of online sources (Adelola, et al., 2010; HSE, 2012a; HSE, 2013a; HSE, 2013b; HSE, 2013c; Mayo Advertiser, 2013; Sealey, 2014; West/North West Hospitals Group, 2014).

As depicted in the table, the national implementation of the UNHS programme was completed by November 2013. In the present system approximately 6,000 infants are screened per month (or circa 72,000 infants per year) across all 19 maternity hospitals in Ireland (HSE, 2014a). According to HSE statistics, a monthly average of 3% of these babies (circa 180 infants) do not pass the screenings and are subsequently referred for further diagnostic testing (HSE, 2014a). The HSE disclosed that approximately 9 of these babies per month (108 infants per year) are diagnosed with "congenital, unilateral or bilateral, moderate to profound permanent childhood hearing impairment (PCHI)" (HSE, 2014a, para 3).

1.5 The Procedure of UNHS

With the widespread implementation of UNHS the HSE routinely disseminates literature to parents of newborn babies explaining the details of the screening. As well as clarifying the purpose and importance of the screening, the literature outlines the procedure in simple language. It explains that the screening consists of an Automated Otoacoustic Emission (AOAE) test which is performed by a trained screener shortly after the baby's birth (HSE, 2013d). The mother can be present and it does not hurt or harm the baby. It essentially involves placing an earpiece in the outer area of the baby's ear while he or she is asleep. This earpiece releases a clicking sound which should cause an echo in the baby's cochlea (the inner part of their ear). This echo is picked up by the screening equipment and the results are given to parents immediately (HSE, 2013d). The literature provides the reassurance that the procedure is unobtrusive and the entire test should take only a few minutes (HSE, 2013d).

The majority of babies pass the screening with a clear result. The occurrence of a "no clear result" (NCR) from one or both ears, indicates that the equipment did not pick up an echo (O'Connor, 2013; HSE, 2013d). Parents receive ample reassurance that an NCR is a common

occurrence and does not necessarily indicate a hearing loss. It can be caused by a variety of factors including background noise, the presence of fluid creating a temporary blockage in the baby's ear after birth, or an unsettled baby (HSE, 2013d). However, with an NCR result, the baby is tested again before leaving the maternity hospital. Significantly, international studies have documented that 80% of babies pass the retest (Clemens et al, 2000).

The repeated screening is performed with either another AOAE test, and/or with an Automated Auditory Brainstem Response (AABR) test (HSE, 2013d). The AABR screening consists of placing soft headphones over the baby's ears and three unobtrusive sensors on their neck and head. Like the previous test, the headphones release clicking sounds into the baby's ears as the equipment tracks any response to the sound (HSE, 2013d). This is a lengthier test which can take between 5 and 30 minutes. If the baby receives another NCR in one or both ears during this second (or third) re-screening they are referred for diagnostic assessment with an audiology clinic (HSE, 2013d). There are presently two care pathways for undertaking UNHS within Irish Maternity Hospitals: A "Well Baby" and a "NICU" (Neonatal Intensive Care Unit) protocol (O'Connor, 2013, p. 551). While both pathways employ the same screening mechanisms, infants who spend more than 48 hours in the NICU ward routinely receive both screens due to the heightened risk factors and the greater prevalence of hearing loss among premature babies (O'Connor, 2013).

In the first year of the UNHS programme in Ireland (before the screening reached national coverage), a total of 525 babies were referred on for audiological diagnostic testing (O'Connor, 2013). This represents an overall referral rate of 4.4 % (O'Connor, 2013). These babies generally received a follow on appointment four weeks after the completion of their screening (O'Connor, 2013). Following the ensuing diagnostic assessment, the average age of a confirmed diagnosis of permanent childhood hearing impairment (PCHI) was approximately 10 weeks (O'Connor, 2013). With the confirmed diagnosis of bilateral hearing loss access to

assistive technology was very prompt, as "babies were fitted with hearing aids by a median age of 11 weeks" (O'Connor, 2013, p. 553). These timeframes stand in stark contrast to those of the previous system. Prior to the implementation of UNHS the screening procedure consisted a "distraction test" when the baby was 9 months old which encompassed "a sensitivity of approximately 40%" and a subsequent "median detection age of 30 months" (O'Connor, 2013, p. 551). Consequently, the radical improvement in timeframes precipitated by the introduction of UNHS is unequivocal.

1.6 Rationale for this Research

This study emerges from the above context but is specifically focused on the issue of *parental coping following early diagnosis of hearing loss in Ireland.* The concern for parental wellbeing is embedded within the NARG Report and the imperative to engage in research on the subject is corroborated by international research. As both these sources form the rationale for this study, each will be examined in turn.

1.6.1 The NARG Report

The NARG Report uncovers three distinct concerns in relation to parental wellbeing. Firstly, it highlights the emotional vulnerability parents experience as they face "the huge implications" of "having a child with a permanent hearing impairment" (NARG, 2011, p. 29). In particular the NARG Report recognises that the experience of receiving a diagnosis can "engender a high level of concern" and distress in parents (NARG, 2011, p. 112). This is most powerfully portrayed through the words of parents themselves:

> Our world fell apart as we were not expecting the news...I remember the next day vividly, sitting in my office wondering who to contact, not having anyone to contact in a very emotional frame of mind...As you can imagine in this difficult time in our lives this situation was extremely upsetting and caused us a great deal of unnecessary stress (NARG, 2011, p. 13).

Thus, the NARG Report expressed concern for these times of acute distress and emphasised that "the period immediately after diagnosis is a crucial period and has lifelong consequences and requires careful and sensitive management" (NARG, 2011, p. 29).

Secondly, the NARG Report included some parents' experiences of receiving little or no support, information, or direction during this period of diagnosis and the immediate aftermath (2011). It documented one parent's particularly poignant experience:

> We were given no information beyond the fact that our son was deaf. We were neither offered the possibility of counselling or other parent support, nor were we pointed in any direction to obtain this for ourselves...We remember clearly leaving that building to sit and cry in our car, with no sense of direction, only a sense of loss. We floundered about using online internet information, and spent days on the telephone reaching out for contacts which could be of help and support. We were at sea (NARG, 2011, Appendix A, p. 6).

Consequently, the NARG Report stressed that "support for parents of children with permanent hearing impairment identified via newborn hearing screening is recognised as a major priority" (NARG, 2011, p. 119). The NARG Report urged clinicians to have sensitivity and concern for emotional vulnerability, particularly as they give information, guide, and support parents.

Thirdly, the NARG Report also portrayed the extent to which the poor coordination of services and substandard equipment did not just affect the child developmentally but also had a detrimental impact on parents' experience of coping. Many parents' provided vivid descriptions of the upsetting challenges and stressful frustrations they faced as they encountered difficulties in the health care system. The Report concedes that:

> Even such apparently minor issues as continual provision of well-fitting ear moulds for the child can, and often does, represent a major stumbling block to progress and for the family's confidence in services. This is evidenced in the consultative exercise undertaken as part of this Review. These issues are vividly highlighted in the many submissions we received from parents (NARG, 2011, p. 29).

Thus, the NARG Report recognised that a consistent, accessible, high quality service is essential to reassure parents and establish their trust and confidence in the system (2011).

These three issues substantiate the purpose of this study. The concern for emotional vulnerability, the acknowledgement of the imperative to provide emotional support, and the recognition of how the coordination of services impacts parental wellbeing, each require further research beyond the confines of the NARG Report. This is of critical importance in progressing the audiology service in Ireland. Thus, the academic rigour of a PhD provides a concentrated context for this important pursuit.

1.6.2 The Affirming Voice of International Literature

International literature also substantiates the imperative to engage in research on the subject of parental coping with an early diagnosis of infant hearing loss. While UNHS had long been established in countries such as the USA, Canada, and the UK, Kurtzer-White and Luterman assert that "there is evidence that our screening endeavours have far outstripped our habilitation efforts, leaving parents with a diagnosis but without support. This gap must be closed" (2003, loc. 39-40). In light of this identification, the literature calls for "a diverse body of research and experiential evidence" to "bridge the gap" between the progressive medical interventions and support for the families in receipt of these interventions (Young & Andrews, 2001, p. 11; Kurtzer-White & Luterman, 2003, loc. 39-40). Young and Andrews recommend that

> each country moving toward the implementation of UNHS will be doing so on its own terms and in its own context... we hope that as each country moves forward with its own particular screening programs, a diverse body of research and experiential evidence will grow that can illuminate the current common and only partly resolved concerns (Young & Andrews, 2001, p. 11).

There is therefore a potent need for Irish academia to implement these international recommendations as a matter of priority and to investigate the impact of UNHS on parental coping within a specifically Irish context. Thus, the international mandate to undertake this study is unequivocal.

1.7 Defining Coping

In examining the subject of parental coping it is important to briefly define (rather than assume) the concept of coping. Lazarus and Folkman define coping as the "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (1984, p.141). As depicted in the careful wording of this definition, coping occurs in the context of psychological and emotional distress which is *taxing* on the individual, perhaps even to the point of *exceeding* their *resources*. As a consequence, coping entails the individual's *efforts* in seeking to *manage* this stress. It is important to highlight that Lazarus and Folkman's selection of the term *manage* does not imply either an adaptive or maladaptive strategy of coping, but incorporates a wide spectrum of responses and may "include anything that the person does or thinks, regardless of how well or badly it works" (Lazarus & Folkman, 1984, p.142). Finally, the definition of coping also portrays it as a *constantly changing* process rather than a singular or stagnant response (Lazarus & Folkman, 1984).

The findings of this study, as detailed in Chapter 6, resonate with each aspect of coping, as defined by Lazarus and Folkman (1984) with the following overview illustrating this point. The data revealed that the anticipation of hearing loss was a distressing time for many parents, the majority of whom experienced acute grief when the unexpected diagnosis was confirmed. This was certainly a *taxing* experience for many families. In addition, it was common for parents to initially struggle to manage their overwhelming vulnerability, and feel as if their *resources* were *exceeded*. Furthermore, the process of adjusting to the diagnosis necessitated extraordinary *effort*. Subsequently, parents described the specific *cognitive and behavioural efforts* they adopted as they sought to *manage* the *internal demands* of emotionally coming to terms with the news. Moreover, parents also explained the *external demands* of taking on a host of new roles and responsibilities to cater for their child's needs. All these efforts, both *cognitive* and *behavioural*, both *internal* and *external*, were *constantly changing* as parents persisted in meeting their child's maturing needs, in combatting challenges in service structure, and continued to refine their understanding of paediatric hearing loss. Thus, Lazarus and Folkman's (1984) depiction of coping is an appropriate definition to undergird this thesis.

1.8 Aims of the Research

This research has two essential aims:

1. Understand the depth and complexity of parental coping as they receive and respond to an early identification of infant hearing loss through UNHS in Ireland.
2. Generate a comprehensive hypothesis from parents' perspectives to conceptualise their journey of coping with an early diagnosis.

In accord with the methodological directions outlined in chapter 4, these aims represent the "substantive" (local) ambition to conceptualise parental coping with the diagnosis of hearing loss in particular, rather than a "formal" (all-inclusive, universal) ambition to generalise coping with all forms of diagnoses (Glaser & Strauss, 1967). While this study is unequivocally rooted in substantive aims, the potential for formal implications will be considered in the concluding chapter.

1.9 Conclusion

Arthur D. Little proposed that "research serves to make building stones out of stumbling blocks" (cited in Fatima & Saeed, 2009, p. 37). The purpose of this introductory chapter is not to reinforce the criticisms detailed in the NARG Report but to acknowledge the background from which this study arises and to locate this research in a climate of positive change. In addition to considering this cultural context, it is also critical to investigate the academic domain from which this study emerges. Consequently, the following chapter will fulfil this requirement by carefully examining the breadth of literature published on the subject of parental coping with UNHS.

2. Literature Review

2.1 Introduction

The issue of parental wellbeing (within the context of UNHS) has been debated in academic literature since the inception of the screening in the 1990s. In particular, the potential to cause (or ease) psychological distress to mothers and the subsequent impact on mother-baby bonding have received a concentrated emphasis. Ironically, these considerations were used by contending authors on both sides of the argument to either endorse or oppose UNHS (Bess & Paradise 1994; Paradise 1999). Over the past three decades, the focus of concerns regarding parental coping has shifted significantly. This chapter will trace this progression from contentious debates at the genesis of UNHS, to the complex explorations of familial issues with the maturation of the screening.

2.2 A Systematic Engagement with the Literature

The research methodology underlying this study stipulated a very specific approach to engagement with the literature. It specified that while the researcher is free to consult the literature at every point of her study, a comprehensive analysis must be delayed until after data collection (see section 4.7 of Chapter 4). Consequently, this ensuing literature review was scheduled in accord with these methodological requirements, and its execution can be broadly summarised in two categorisations.

Firstly, a comprehensive analysis of the literature necessitated a systematic search. The author employed five academic databases (*Academic Search Complete, First Search, Web of Knowledge, J-Store,* and *Scopus*) to methodically locate pertaining literature. The search terms were judicious, and techniques such as truncation, Boolean logic, phrase searching, and thesauri were utilised with discretion. The search was confined to the specific subject of

parental coping with the early identification of their child's hearing loss. This computerised search was substantiated by a manual search. Having compiled a list of relevant articles, the researcher proceeded to manually sift through the bibliographies of key articles to source important cited works. She also located the further publications of key authors in order to examine their body of literature. In addition, she also traced the academic dialogue within the literature, observing publications which cited and built upon key articles. This manual search was important to source articles that may not have been identified by the databases. The 68 resultant articles were compiled in a spreadsheet (see Appendix A), with distinguishing columns detailing significant features of each publication (year, author, research methodology etc.). This ensured transparency and ease of comparison. All publications were scrutinised under the strict criteria of relevance and any extraneous material was disregarded. Thus, the literature review omitted issues such as the question of cochlear implantation or language acquisition. This exclusivity was essential to ensure a concentrated and in-depth focus.

Secondly, the results of the systematic search were scrutinised with a systematic analysis. The researcher undertook a citation analysis to determine the impact factor of each article and ascertain its influence in the academic community. The academic database *Scopus* was selected as the optimal tool to calculate this measurement. The ensuing computation of the impact factor of each article efficaciously highlighted which publications were particularly seminal in shaping the academic discourse. The spreadsheet of articles was subsequently reordered to reflect this citation analysis. The articles were ranked in descending order according to their impact factor (see Appendix A). However, this hierarchical ordering of literature was not taken as a perfect measure of an article's importance or influence in the academic community. For example, recently published articles inevitably exhibit a very low impact factor and fare poorly in a citation analysis, which does not reflect the merit of their content or the influence they will render in time. Nevertheless, despite these limitations, a

citation analysis remained helpful in pinpointing the specific articles and arguments that have been particularly influential in the specific field of parental coping with UNHS. Significantly, this guided the researcher's analysis and portrayal of the competing arguments embedded within the literature.

The systematic search and analysis facilitated a robust and comprehensive engagement with the literature. Importantly, it enabled the researcher to identify the prominent arguments, articles, and authors within this specific field of study. The remainder of this chapter will build on this systematic foundation and provide a critical analysis of the literature.

2.3 Genesis

The prospect of an early identification of hearing loss was not universally welcomed at the genesis of the newborn screening in the early 1990s. The potential of psychological distress caused to mothers were among the controversial issues that raised concerns. During this tentative introduction of neonatal hearing screening, Bess and Paradise published a contentious article entitled *Universal Screening for Infant Hearing Impairment: Not Simple, Not Risk-Free, Not Necessarily Beneficial, and Not Presently Justified* (1994). This article continues to claim the highest impact factor in the citation analysis of this literature review. As well as asserting that there was no proof that early intervention at 6 months, rather than 18 months, would yield significant developmental advantages for the baby, Bess and Paradise argued that the potential psychological distress caused to the family is unjustifiable (1994). In particular they predicted that the inaccuracy of the screening would yield an unprecedented false-positive rate that would precipitate undue parental anxiety and cause the unwarranted "disturbance of family function" and formation (Bess & Paradise, 1994, p.332). Bess and Paradise (1994) contended that it is

inappropriate to impose this anguish on families, particularly for those who will later pass this screening. They asserted that there is no conclusive evidence that this system of intervention "results in more good than harm to the child and family" (Bess & Paradise, 1994, p.332).

As neonatal hearing screening was implemented more widely in the USA, despite Bess and Paradise's protestations, Paradise reinforced these criticisms in a subsequent article entitled *Universal Newborn Hearing Screening: Should We Leap Before We Look?* (1999). Paradise claimed that the first stage of the newly implemented screening generated a false-positive rate that surpassed 90% (1999). He emphasised the harmful consequences this may engender for families, particularly with regard to unprecedented parental anxiety and the impact of "unfavourable 'labelling'" on parent-child bonding (Paradise, 1999, p.670). Paradise substantiated his concern by pointing to related studies examining "other types of newborn screening" which asserted that

> identifying a child as abnormal in the newborn period, even when that identification soon proves incorrect, can precipitate lasting anxiety on the part of certain parents and can have long-term adverse effects on parent-child relationships and on children's later psychological development (1999, p.671).

Significantly, in a rebuttal against the lack of research examining the attendant costs and risks incurred by UNHS, Paradise called for a "large randomized clinical trial" that would provide a "follow-up for all children incorrectly identified as having hearing loss" and examine the "degree of the parent's stress and anxiety" (1999, p.672).

2.4 Rising to the Challenge

Countless studies responded to this challenge and counteracted Bess and Paradise's assertions with regard to the false-positive rate and resultant family discord. One of the most

influential and comprehensive responses was undertaken by Clemens et al (2000). Significantly, this study directly referenced both articles penned by Bess and Paradise (1994) and Paradise (1999), thus creating a dialogue of concepts.

Clemens et al specifically examined Bess and Paradise's two criticisms of the high false-positive rate and the question of lasting maternal anxiety. This study encompassed "a retrospective analysis" whereby the authors examined the screening data relating to 5010 infants in the Women's Hospital of Greensboro in the USA, and also undertook a "structured telephone" survey with mothers whose child failed the inpatient screening but later passed their outpatient rescreen (2000, p.1). In the initial stage of inpatient screening (which is broadly defined as the period prior to discharge from the maternity hospital) Clemens et al documented a false-positive rate of 1.9% (2000). This statistic stands in stark contrast with Paradise's assertion of 90% (1999). Clemens et al highlighted that this low rate was a consequence of the proficiency of the screening device (the AABR test) in addition to the rescreening of 51% of babies prior to discharge (2000). Of these rescreened babies, 80% passed the retest thus dramatically reducing the resultant false-positive rate. Clemens et al (2000) calculated that an automatic rescreen of all (rather than some) infants prior to discharge would further reduce the false-positive rate to <1%. This dramatically lower percentage silences the siren sounding from Bess and Paradise's argument.

Bess and Paradise do not appear to have published a rebuttal to these statistics and, indeed, numerous other studies confirm Clemens findings and critique Bess and Paradise's assertions. In particular, Young and Andrews (2001) criticise Paradise's sources in calculating a 90% false-positive rate, observing that the studies he cites calculate the "percentage of the total number of all infants screened (regardless of the outcome of stage 1 testing) who, at the end of the whole screening process, are found to be hearing" (p.151). Consequently, this is not

an accurate representation, or indeed an appropriate computation, of the percentage of babies who fail the inpatient hearing screening but later pass.

With this significantly lower false-positive rate, the question of unnecessary parental anxiety arising from a false-negative screen is a demonstrably less prevalent occurrence. Nevertheless, it remains a legitimate concern which Clemens et al also addressed in their study (2000). They found that 80% of mothers expressed some degree of worry during the interim period between failing the initial inpatient screen and waiting for the outpatient rescreening (Clemens et al, 2000). However, Clemens et al found that 91% of mothers[4] reported no change in their (or the family's) treatment of their baby during this time (2000). Furthermore, having passed the subsequent outpatient re-screen, 86% of parents claimed to have "no lasting anxiety", 12% described only "mild anxiety", and only 2% (one parent) testified to "much anxiety" (Clemens et al, 2000, p.3). Clemens et al concluded that "initial feelings of anxiety are common but dissipate quickly after the child passes stage 2 screening" (2000, p.4). They asserted that this modest false-positive rate is unlikely to engender lasting maternal anxiety or generate a "vulnerable child syndrome' (2000, p.4). Furthermore, numerous studies argue that even the initial feelings of worry or anxiety after the first failed screen can be significantly dissipated by providing good information to parents (beginning in pregnancy), by ensuring parents are present at the screen, by employing neutral language in communicating the results (*refer* rather than *fail*), and by offering ample reassurance and support to parents (Clemens et al, 2000; Manguson & Hergils 1998; Weichbold et al, 2001; Hergils & Hergils, 2000).

A myriad of studies have substantiated Clemens et al's conclusions (2000), independently producing comparable results, and concluding that false-positive testing does

[4] The remaining 9% of parents described changed responses such as testing their baby's hearing (by clapping hands) or speaking in louder volume.

not incur long term parental anxiety or disrupt parent-child bonding (Van Der Ploeg et al, 2008; Vohr, 2008, Hergils & Hergils, 2000). In particular, Manguson and Hergils (1998) undertook a study of 49 parents to examine the "feelings, thoughts, and opinions" of parents who had experienced newborn hearing screening (p.47). This study claims a high impact factor in the citation analysis. It concludes that there is little to no maternal anxiety caused in the screening process and, although a degree of stress is incurred in the experience of a false-positive result, this did not negatively affect the parent-child relationship or result in lasting anxiety (Manguson & Hergils, 1998). Indeed the study confirmed parental anxiety could be significantly eased with good support, communication, and information. Thus, the study demonstrates that the risk of false-positive screenings does not signify an ethical obligation to prohibit the introduction of UNHS.

In addition, Manguson and Hergils, along with a myriad of studies, have consistently verified parental satisfaction with UNHS testing. The overwhelming majority of parents consistently expressed their strong support of the screen (Manguson & Hergils, 1998; MacNeil et al, 2007; Hergils & Hergils, 2000; MacNeil et al, 2007). Indeed many parents even advised it should not only be universal but also mandatory, pointing out that a late diagnosis has the potential to cause parental distress and anxiety (Manguson & Hergils, 1998, Hergils & Hergils, 2000). Thus, a number of studies not only responded to, but also resolved, the concerns raised by Bess and Paradise.

2.5 An Imbalanced and Inadequate Treatment

The sheer volume of publications arising on the specific subject of maternal anxiety (on account of a false-positive outcome) is disproportionate to other important considerations. This

unprecedented attention is explained by the context of the contemporaneous criticisms that UNHS was unethical. It is understandable then that an abundance of articles subsequently arose to combat these criticisms and prove that UNHS does not cause undue harm to families. Nevertheless, the over-emphasis on false-positives and consideration of only one emotion (namely anxiety) neglected an in-depth treatment of the complex emotional response arising from true-positive cases where parents did receive a diagnosis of their child's hearing loss.

While a minority of early studies took exception to this trend they provided an inadequate treatment of the subject. For example, Manguson and Hergils (1998) did incorporate a consideration of true-positives in their influential study of parental experiences of UNHS. However this consideration appeared as a facet within a larger research endeavour rather than as a concentrated emphasis and, subsequently, produced an insufficient investigation of this subject. In particular, only 8 of the 49 parents who participated in Manguson and Hergils' (1998) study experienced the full diagnostic testing with a resultant diagnosis of their child's hearing loss. The remaining 41 passed the screening either immediately or during the follow-up re-test. Manguson and Hergils (1998) took a strikingly positive stance in depicting the experience of the 8 true-positives, and asserted that "anxiety diminished when parents were told the final result, when the parent-doctor contact had been established, and when a plan for action could be outlined" (Manguson & Hergils, 1998, p.55). They concluded that with a definitive diagnosis and a plan of action, the parents' "anxiety seemed to fade" (Manguson & Hergils, 1998, p.47). However, this optimistic generalisation represents an insufficient treatment of the subject as it fails to take account of the plethora of emotions parents experience during the diagnostic period, it depicts an overly simplistic and quixotic resolution of anxiety, and neglects a consideration of the process of family adjustment.

It is important to balance these criticisms. The intent of Manguson and Hergils' article (1998) appears to be to advocate for the benefit and necessity of UNHS at a time when it was criticised as unethical due to its potential to disrupt family function. With this context in mind, their optimistic depiction of a quick resolution of anxiety in the case of true-positives is understandable, albeit misleading. While Manguson and Hergils' research is helpful in advocating for the nationwide implementation of UNHS, it does not deal adequately with the issue of how to support parents who experience the turmoil of an unexpected diagnosis.

A further limitation arising from many studies that consider parents' distress is their selection of instruments. Yoshinaga-Itano has produced some of the most influential research, pioneering the necessity of UNHS. In particular her publication in 1998 has been acknowledged as a "landmark article" which "removed any lingering doubts…that early identification truly makes a difference in outcomes for children" (2014, EHDI Conference, p.20). In 2014 she was awarded the "Antonia Brancia Maxon Award for EHDI[5] Excellence" as a mark of recognition that "she is part of the elite few who have made newborn screening the standard of practice for newborns, worldwide" (2014, EHDI Conference, p.20). However, while Yoshinaga-Itano's study of language development is renowned, her treatment of parental emotional distress is limited (2003b).

In her series of seminal articles examining the outcomes of early intervention following UNHS, Yoshinaga-Itano draws together an array of data from a multi-faceted and longitudinal series of studies spanning from 1994 to 2001 in Colorado, USA (2003a, 2003b, 2003c). In these articles, she examines family issues as one factor within larger survey. As a consequence, while she certainly identifies these important considerations, she does not

[5] EHDI is an acronym for *Early Hearing Detection and Intervention* – the national early identification and intervention programme for children with hearing loss in the USA. This award was presented to Yoshinaga-Itano during the annual EHDI conference in April 2014.

provide an in-depth examination of emotional response and relationships. Furthermore, in detailing the component of the study which centred on parental stress and attachment, Yoshinaga-Itano highlights the use of fixed quantitative measures (2003b). In particular the *Parental Stress Index*[6] was selected as the instrument of choice and utilised with a large sample of 184 mothers[7] (Yoshinaga-Itano, 2003b). However, there are a number of restrictions associated with this measure.

Firstly, the *Parental Stress Index* is a generic tool which is not specifically designed to examine the unique circumstances and dynamics of caring for a child with a hearing loss Secondly, by providing parents with fixed scales and closed questions, the study does not allow them to express the depth, subtlety, and complexity of their experience in their own words. Thirdly, parents may have answered according to what they believe should be the correct parental response, rather than according to their actual experience. This tendency could arise out of a sense of guilt or a fear of not wanting to be labelled as a bad parent. Finally, all parents were sent the questionnaires at 6-month intervals, which implies that parents were conveying their present emotional state during the early intervention stage of their journey, rather than retrospectively describing their emotional wellbeing during the diagnostic process. As a consequence, it appears that the instrument may be measuring parental stress during intervention, rather than during diagnosis. Thus, their emotional response to the diagnosis itself appears to be overlooked within this study.

These limitations, incurred by this measurement tool, influence the subsequent conclusions. Yoshinaga-Itano's data indicated that "mothers in this study demonstrated significantly less parental distress" in comparison to the "normative, hearing group" (2003b,

[6] The "Parenting Events/Daily Hassles Scale" was also utilised in this study, which is subject to the same limitations as listed in the subsequent paragraph (Yoshinaga-Itano, 2003b).
[7] Yoshinaga-Itano gives credit to Pipp-Siegel et al (2001) for undertaking the field-work.

p.264). However, this conclusion presents a flat analysis of the parental emotional response, reducing it to the one emotion of stress and presenting it as comparable to that of the general population. Interestingly, Yoshinaga-Itano qualifies her conclusion. She concedes that this lower level of distress is influenced by the absence of secondary medical complications, by family's participation in home intervention programmes, and by the child's successful language development (Yoshinaga-Itano, 2003b). Elsewhere Yoshinaga-Itano indicates that families also receive counselling support, guidance, information, and education from programme coordinators who are specifically trained to support families (2003a). Consequently, it appears that the results of low-level stress are could be more indicative of the influence of a successful early-intervention programme, rather than an accurate portrayal of the parent's emotional journey. Thus, while the findings corroborate the benefit of systems of support, they do not plumb the depth of parent's emotional response to the diagnosis, or explore the process of parental adjustment and coping. It is possible that this consideration was not the intent of Yoshinaga-Itano's investigation, and therefore not necessarily a shortcoming of her publication *per se*. However, it reflects the propensity within the wider body of literature to consistently neglect an in-depth exploration of the parental experience.

2.6 Protesting the Imbalance

A number of authors highlighted this pattern of inattention arising from the wider body of UNHS literature. In particular the following four independent groups of authors published their criticisms:

- Luterman and Kurtzer-White (1999) complained that "no study to date has solicited the opinions of parents of deaf children as to when and how babies and their families can best be served at the time of diagnosis" (p.14). By 2003, they protested at the

inattention that the subject continued to receive "despite the evident importance of it" (Luterman & Kurtzer-White, 2003, loc.34-35).

- Young and Tattersall[8] (2007) objected that "far less attention has been paid to the impact of the deaf child on the family and processes and patterns of family adjustment" (p.209).
- Russ et al (2004) criticised that "studies examining parent's perceptions of the screening and diagnostic process are ... few in number" (p.353).
- Fitzpatrick et al (2007) evaluated that "relatively little attention has been paid to the social-emotional aspects for the child and family" and highlighted the necessity of investigating the effects an early diagnosis from the perspective of parents (p.105).

The citation analysis revealed that these four groups of authors have been particularly seminal in not only challenging the disparity they observed but also in producing literature with a high impact factor that redressed this imbalance. The remaining segment of this literature review will pay close attention to their influential publications (articles with a lower citation analysis will be weaved in at appropriate junctures).

2.7 A Paradigm Shift

While strongly affirming the necessity and benefit of UNHS, these studies explore the "changed conditions" of early identification and intervention (Young & Tattersall, 2007, p.218). In particular, they highlight that the diagnosis of hearing loss is now precipitated by routine screening at birth rather than initiated by parental suspicions generated over time. Thus, UNHS represents "a paradigm shift" from a "parent-initiated model of diagnosis to an

[8] Young & Tattersall have also co-written further important publications in conjunction with a number of other authors including Carr, Hunt, McCracken, Skip, Gascon-Ramos, Campbell, Bamford and Andrews.

institution-initiated model" (Luterman & Kurtzer-White, 1999, p.16; Kurtzer-White & Luterman, 2003, p.232). This paradigm shift has a number of implications for the parental experience of receiving a diagnosis, and their subsequent process of adjustment. In particular six overarching themes reverberate in the publications, evoking both consensus and contention between these four groups of authors. These six themes will each be explored in turn.

2.7.1 Timing and Bonding

Firstly, the "paradigm shift" of UNHS, has significant implications for parental preparation (Luterman & Kurtzer-White, 1999). Irrespective of timing, the diagnosis is associated with considerable shock: 90% of deaf babies are born to hearing parents with little or no prior experience or exposure to the world of hearing loss (Kurtzer-White & Luterman, 2003). Not only do parents have no reason to expect their child may have a hearing loss, during pregnancy parents build up aspirations of what their new lives will encompass with their expectant baby that implicitly assume their child will hear and speak (Kurtzer-White & Luterman, 2003). The sense of shock arising from the unexpected diagnosis is particularly palpable for parents who receive a diagnosis through UNHS. Within the "highly compressed timescale" of early identification, the diagnosis is no longer precipitated by parental observations but by a routine screening (Young & Tattersall, 2007, p.210). Accordingly, the prospect of a hearing loss does not have a context of parental suspicion to engender a sense of preparation or expectancy (Kurtzer-White & Luterman, 2003). Thus, the shock of an unforeseen diagnosis can be reinforced by UNHS and experienced more acutely (Fitzpatrick et al, 2007; Kurtzer-White & Luterman, 2003).

Furthermore, with the inception of UNHS the shock of an unexpected diagnosis now occurs during a vulnerable and tender time for the mother, who is still recovering from the

physical and emotional demands of birth and forging a bond with her newborn baby. This is also a critical time of family formation when parents and siblings are establishing new identities, roles, and responsibilities (Kurtzer-White & Luterman, 2003). While this issue was previously highlighted in the context of false-negatives, the magnitude of a true-positive result is distinctive, as the mother deals with the reality (rather than the mere possibility) of her baby's hearing loss. Accordingly, Kurtzer-White and Luterman imply that the distress of facing this unexpected diagnosis "during such a vulnerable and critical time" can impact parent-child bonding (2003, p.233). They highlight that parents are devoid of time to enjoy their child free from the worry and grief of a diagnosis (Kurtzer-White & Luterman, 2003; Young & Tattersall, 2007).

While subsequent studies certainly corroborate these considerations, they also provide counter-arguments. Young and Tattersall (2007) suggested that an early diagnosis may engender better parent-child bonding. They propose that a later diagnosis may precipitate a disruption in the parent-child relationship, as parents are faced with the disparity between their previous perception of the child as hearing, and the revelation of the child as deaf. This shift in perspective, may be more difficult in the context of an already established relationship with assumed identities (Young & Tattersall, 2007). Fitzpatrick et al, drew similar conclusions as they found that "some families felt that it was better for the child's self-concept to have been identified in infancy both for the child herself and for the family with respect to accepting the child as an individual with a hearing loss" (Fitzpatrick et al, 2007, p.102). Parents in this study articulated that it would have been a bigger adjustment for the family to experience a shift in the child's identity after a few years of establishing a relationship with him/her (Fitzpatrick et al, 2007). A later diagnosis is therefore not necessarily a better context to safeguard parent-child bonding.

Importantly, Young and Tattersall (2007) and Fitzpatrick et al (2007) do not present these counterarguments as emphatic or absolute. Both studies acknowledge the perspective of a minority of parents who complained that anxiety and grief tainted their earliest memories with their newborn baby. However, while both studies nuance their assertions with this inclusion, they nevertheless affirm that the "overwhelming majority" of parents "were unequivocally positive…that their child's deafness had been identified early" (Young & Tattersall, 2007, p.213; Fitzpatrick et al, 2007). Indeed numerous studies corroborate that parents who received a *late* diagnosis of their child's hearing loss are often the most emphatic advocates for an *early* diagnosis (Fitzpatrick et al, 2007).

2.7.2 The Emotional Response of Parents

The second theme which the seminal publications consider at length is the emotional response of parents to their child's diagnosis. Kurtzer-White and Luterman (2003), Young and Tattersall (2007), Russ et al (2004), and Fitzpatrick et al (2007) all agree that parental grief in response to the diagnosis of their child's hearing loss is a complex response and encompasses a flood of strong emotions including shock, numbness, disbelief, denial, avoidance, protestation, fear, worry, anxiety, sorrow, upset, anger, helplessness, hopelessness, despair, insecurity, as well as feeling threatened, overwhelmed and inadequate to manage their child's needs. This stands in utter contrast with Manguson and Hergils' (1998) reduction of parental emotional response to one simplistic trait.

In addition to challenging the oversimplification of grief, these articles also challenge the oversimplification of its resolution. Young and Tattersall (2007) reference Siegel's (2000)[9]

[9] Young & Tattersall (2007) specify that their reference to Siegel (2000) is in the context of Yoshinaga-Itano & de Uzcategui's (2001) citation of his study.

suggestion "that earlier identification can lead to a quicker resolution of parental grief processes among hearing parents" (Young & Tattersall, 2007, p.210). However, Young and Tattersall (2007) as well as Kurtzer-White and Luterman (2003) repudiate this conclusion on three different levels. Firstly, Young and Tattersall (2007) criticise the methodology of the study that gave rise to this assertion, suggesting that it consisted of a "small pilot study" which failed to distinguish the "mediating variable" of reduced stress arising from efficacious early intervention and improved language acquisition (2007, p.210). Secondly, Young and Tattersall (2007) as well as Kurtzer-White and Luterman (2003) deny the implicit assumption that parental grief is resolvable. While they acknowledge that the initial intensity of parental grief softens with time, they argue that it is not a finite entity as it has the capacity to resurface at different stages throughout the child's life (Kurtzer-White & Luterman, 2003; Young & Tattersall, 2007). In particular, important milestones at critical points throughout the child's life may represent "trigger events" which precipitate a contrast between what is and might have been (Kurtzer-White & Luterman, 2003, p.234). This juxtaposition may engender a renewed sense of loss and mourning. Thus, "parental grief and sorrow, and the impact of hearing loss on families must be acknowledged then, not only at the time of diagnosis but over the course of the child's developmental life" (Kurtzer-White & Luterman, 2003, p.234). Finally, Young and Tattersall (2007) also argue that the simultaneous emotions of grief and reassurance engendered by UNHS, create a "precarious context" which undermines any simplistic proposition of a reduced impact or more swift resolution of grief (p.217).

As well as contending that grief is not finite, Kurtzer-White and Luterman also argue that neither is it formulaic, rigid, or experienced in a linear fashion, with successive predictable stages which conclude with a resolution. With these principles in mind, Kurtzer-White and Luterman (2003) strongly criticised the inappropriate application of grief-models associated with terminal illnesses to the parental experience of UNHS. They described that the commonly

cited Kubler-Ross model of the five stages of grief is based on research undertaken with terminally ill patients, and consists of specific and sequential stages in coming to terms with the end of life. Kurtzer-White and Luterman (2003) highlight that "there is a significant difference between the symbolic loss of the idealized child and parent's own identities and the real, physical loss that death brings" (Kurtzer-White & Luterman, 2003, p.234). Furthermore, they argue that applying this specific model to the realm of infant hearing loss creates a false expectation that "parents will in fact resolve their grief as if it were time-limited and episodic" (Kurtzer-White & Luterman, 2003, p.234). Significantly, while the "powerful emotions" engendered by the diagnosis fade over time, they never dissipate completely (Russ et al, 2004, p.356; Kurtzer-White & Luterman, 2003; Young & Tattersall, 2007).

2.7.3 Uncertainty and Urgency

The third theme impacted by the "paradigm shift" of UNHS, is the attendant sense of uncertainty and urgency parents experience. Lutternam and Kurtzer-White argue that a sense of uncertainty pervades both an early and late diagnosis (1999). They highlight that as parents receive the unexpected diagnosis they are also faced with the uncertainty of the child's future (Kurtzer-White and Luterman, 2003). At the point of diagnosis audiologists may not be able to offer conclusive answers to parents, particularly regarding questions of language development and schooling. As a consequence, parents "are presented with a diagnosis that is unexpected and a future for their child that is uncertain, unpredictable, and ambiguous" (Kurtzer-White & Luterman, 2003, p.233).

Young and Tattersall raise a further time-related dilemma (2007). While acknowledging the benefits of early identification, Young and Tattersall argue that an early diagnosis can create a sense of time pressure for some parents (2007). They documented that

for other parents the "early knowledge-inducing timetables of expectations" can precipitate "distress when not met speedily" (Young & Tattersall, 2007, p.209). Young and Tattersall argued that with an early diagnosis parents can have high hopes of maximising the advantages arising from an early diagnosis with the underlying belief that "the best possible outcome will only be realised if action occurs quickly and on time" (2007, p.217). This created a sense of being on a "timetable" to ensure the child does not miss out on developmental advantages, and incurred feelings of "pressure and further distress" (Young & Tattersall, 2007, p.217; McCracken et al, 2008).

However, both these contentions are disputable. Kurtzer-White and Luterman (2003) fail to highlight that concerns regarding the uncertainty of language acquisition and school placement are more immediate and threatened for parents of later identified children. Fitzpatrick (2007) observed that "the language delay associated with later identification" generated a sense of "urgency" and "lost time" in parents, who experienced the "frustration that time was running out" (p.102). One parent in Fitzpatrick's study articulated the "stress" of "constantly playing catch up" and despite extensive effort and intervention observed that her child is "still behind" which she described as "deflating to his childhood" as it caused social isolation from his peers (p.102). Furthermore, this delayed communication and social development may carry into schooling and have significant implications for educational options. Russ et al highlight that "children experiencing very late diagnosis of mild and moderate losses had often struggled in the school system, requiring extra assistance and grade repetition" (2004, p.357). Consequently, the uncertainty, stress, and frustration with regard to language and schooling is augmented with a late diagnosis and late intervention. In contrast, it is significantly eased with an early diagnosis because parents have the reassurance that with early intervention their child has the best opportunity to develop communication (be it sign or speech) on a par with their hearing peers (Young & Tattersall, 2007).

Similarly, Fitzpatrick et al present a counter argument to Young and Tattersall's concern (2007). They contend that parents who receive a later diagnosis experience this same pressure of being on a developmental timetable, coupled with the additional stress of starting from (what they perceive to be) a compromised position and desperately trying to catch up (Fitzpatrick et al, 2007). This study documented that parents who received a later diagnosis reported that "they had little time to investigate the options for their child's communication development" before making a decision (Fitzpatrick et al, 2007, p.102). These parents demonstrated a greater urgency in seeking intervention services and assistive technology, and expressed greater frustration with poorly coordinated services or delayed access (Fitzpatrick, 2007). Significantly, Fitzpatrick et al observed that this sense of urgency, frustration, and stress was significantly eased with an earlier diagnosis (2007).

2.7.4 Coping

An important (but less emphasised) theme arising from the seminal publications, is the issue of parental coping. The manner in which parents respond to the child's diagnosis is important not only in terms of the parent's own psychological wellbeing, but also in terms of the child's socio-emotional and linguistic development. Yoshinaga-Itano substantiates the link between language development and maternal sensitivity (2003c). She confirms that "the degree to which mothers are sensitive to their children's emotional needs is highly related to the rate of vocabulary development of children who are deaf or hard of hearing" (Yoshinaga-Itano, 2003c, p.205). Likewise, Kurtzer-White and Luterman reference Pressman et al (1999) in their assertion that "the emotional climate of the parent-child relationship is a necessary context for the unfolding of child development in many domains, including exploration and competence in the physical, social, and linguistic worlds" (Kurtzer-White & Luterman, 2003, p.232;

Jackson 2009). Thus, the capacity of parents to adjust and cope with the unexpected diagnosis, and their consequent engagement with their child, has tremendous implications.

Interestingly, the literature does not deal extensively with the question of how parents manage their overwhelming grief, or the process by which they learn to adjust and cope. However, two concerns are identified in relation to parental coping. Firstly, Kurtzer-White and Luterman, (2003) identify a subtle form of denial, which they classify as the coping mechanism of *normalisation*. This form of denial, is not a rejection of the hearing loss itself but a rejection that their child and life will be any different because of it. Kurtzer-White and Luterman (2003) argue that this is a finite and flawed coping mechanism because the parent will inevitably encounter "trigger events" which will expose the veracity of the situation, "pierce the bubble" of their denial, and leave them struggling to accept "a new reality" and the changes it presents (Kurtzer-White & Luterman, 2003, p.234). Kurtzer-White and Luterman, (2003) describe that an important point for parents is to acknowledge the loss, and recognise the difference it engenders, for their child, their lives, and their family. However, Kurtzer-White and Luterman (2003) do not consider the opposite danger to "normalisation"; the mistake of stressing the child's difference to the extent that it is estranging or alienating. However, perhaps their guiding principle, that "acceptance is a necessary prerequisite of a successful hearing impaired child", guards against these equal and opposite dangers (Kurtzer-White & Luterman, 2003, p.235). A counter to denying the effects of hearing loss, can be the alternative coping mechanism of proactivity. Young and Tattersall (2007) express caution that an undivided focus on activity can lead to an evasion of grief, and circumvent the important process of coming to terms with loss. This theme is explored in more depth in the Discussion Chapter of this thesis. Significantly, while both articles (Young & Tattersall, 2007; Kurtzer-White & Luterman, 200) highlight isolated responses to managing grief, neither offer a comprehensive exploration of a range of coping mechanisms.

However, a study undertaken by Md Daud et al (2013) indirectly addresses this gap. The low impact factor of this article may be indicative of its recent publication date rather than an appraisal of its significance. While focusing more on gender differences, this study analysed and contrasted the coping mechanism of 36 fathers and 36 mothers, with the objective of understanding differences in male and female coping styles. The results revealed both similarities and differences. The two groups differed in their choice of "problem-focused strategies" but interestingly were similar in "emotional-focused strategies" (Md Daud et al, 2013, p.319). In particular, the study found that "the domains of religion, seeking emotional support, and seeking instrumental support scored significantly higher in mothers than in father" (Md Daud et al, 2013, p.319). This study is significant, not just in its consideration of alternative coping mechanisms which come more naturally to men and women, but in its subsequent recommendation that services should consider these gender differences in seeking to support parents.

2.7.5 Information and Worldviews

The theme of information and worldviews has generated considerable attention in the literature. Kurtzer-White and Luterman (2003) highlight the difficulty of presenting parents with technical and specialised information at a point of acute emotional vulnerability. Not only is this information difficult for parents with no background in the discipline, it can also be charged with competing worldviews, political ideologies, and emotive arguments. Parents are required not only to process this complex and charged information but also to act upon it as they make critical choices regarding early intervention options, communication choices etc. Kurtzer-White and Luterman highlight that this is both "emotional and challenging" for the parents (2003, p.233). Furthermore, parents habitually turn to the internet for information, and the quality of the material they access is questionable (Porter, 2003).

Young pays particular attention to these competing worldviews of hearing loss, which is a recurrent theme in many of her articles. She broadly differentiates two conflicting ideologies. Firstly, she outlines the *medical model* of hearing loss, which presupposes a *deficit* view of deafness, assuming it needs to be managed in a medical capacity (Young et al, 2006; Young, 1999; Mattijs et al, 2012). This worldview is contrasted with the alternative *cultural-linguistic model* of deafness, which embraces hearing loss as a positive *difference* rather than a negative *deficiency* (Young et al, 2006; Young, 1999; Mattijs et al, 2012). These two ideologies depict two conflicting representations of deafness as either a disability which imposes limitations, or alternatively as an identity within a cultural minority (Mattijs et al, 2012). Alternative communication options (such as cochlear implantation or sign language) can be associated with these conflicting worldviews and can be charged with ideological and political significance. Significantly, the provision of services and care-pathways available to families are often differentiated by these competing ideologies. While mainstream services are typically underlined by the ethos of the medical model (to the exclusion of the cultural-linguistic model), the reverse can also be true (Bosteels et al, 2012; Mattijs et al, 2012).

From the perspective of the UK services, Young et al observe (2006) that parents of newly diagnosed children are often presented with the options associated with one ideology while the counter is either "denied" or "unacknowledged" (p.323). The exclusion of either discourse (in particular the omission of the cultural-linguistic model from early intervention services) may be caused by the lack of available resources or could be indicative of the bias of a particular professional/service (2006). This omission occurs on a number of levels:

1) In professional-parent discourses during screening, diagnosis to intervention (Young & Tattersall, 2007; DesGeorges 2003; McCracken et al, 2008; Bosteels et al, 2012).

2) In the selective provision of written information which is disseminated to parents (Young et al, 2006).
3) In the selection (or omission) of intervention/communication options offered to parents (Young et al, 2006).

Young et al argue that this can have significant implications, not only for the choices parents make regarding care-trajectories[10], but also in forging the expectations and attitudes parents subsequently foster in relation to their child as well as their understanding of the child's identity (Young et al, 2006, Young & Tattersall, 2007).

2.7.6 Supporting Systems and Professionals

The final, and related, theme arising from the collection of influential publication is the question of what systems of services successfully support parents through their arduous journey. There is consensus that early identification should go hand in hand with early intervention because without the latter, the former would be unethical, yielding no benefit for the child or family (Young & Tattersall, 2007; Yoshinaga-Itano, 2003c; Brown & Mackenzie, 2005). Importantly, delays in intervention or lack of coordination in services consistently incurred a sense of distress, anxiety, disempowerment, and frustration for families (Russ et al, 2004, Young & Tattersall, 2007; Fitzgerald et al, 2007; Hardonk et al, 2011). However, with this principle in mind, Young and Tattersall caution that the system needs to be "mindful to create the space for parents to feel their responses to their child's deafness" rather than launching into a rush of activity too quickly (2007, p.217; Bosteels et al, 2012). Particularly in light of the "highly compressed timescale" in which parents receive the diagnosis of their child's hearing loss, a balance is needed between responsive, timely services, and allowing

[10] This subsequent question of parents informed choice, is explored at length by Young et al (2006). However, an in-depth consideration of this subject is outside the scope of this literature review.

space for parents to process the significant life change (Young & Tattersall, 2007, p.210). Interestingly however, no parent in Young and Tattersall's study, or indeed any other study in this literature review, expressed that early intervention was too early (Young & Tattersall, 2007). While early intervention certainly did not lessen or resolve grief, it certainly brought a tremendous reassurance to parents.

As well as the importance of cohesive, coordinated, and timely framework of intervention, the professionals who embody these services are pivotal. The parent-professional relationship was identified by Tattersall and Young (2006) as the most significant determining factor of parents' experience. In particular, the professional's capacity to communicate effectively with the parent is consistently highlighted as essential (Young & Tattersall, 2006; Fitzgerald et al, 2007; Minchom et al, 2003). From the parental perspective, Tattersall and Young (2006) found that parents defined good professional communication in terms of clear explanations and sensitive interactions, as well as honest, open, and inclusive engagement with families. Interestingly, parents across a number of studies also stressed the imperative for clinicians to allow adequate time to engage with parents effectually and emphasised that they should be adept at translating technical information into ordinary language to ensure parental comprehension (Russ et al, 2004; Luterman & Kurtzer White, 1999). Parents also articulated that good communication should dovetail good professional manner, which should encompasses a patient, approachable, and accommodating disposition (Tattersall & Young, 2006).

Conversely, Russ et al documented traits of poor professional communication from the perspective of parents. Russ et al documented that parents frequently reported "communication difficulties" with providers (Russ et al, 2004, p.357). Parents described the stress of miscommunication, misunderstandings, unclear explanations, confusion, and "misleading or incorrect advice", all of which had negative implications for parental wellbeing and care related

decisions for the child (Russ et al, 2004, p.356; Kelly & Bibby, 2008). From the clinician's perspective, the responsibility to communicate technical results clearly yet sensitively is a challenging prospect as they "may have been attempting to give quite complex explanations about a child's audiological status at times when parents were experiencing intense emotional reactions" (Russ et al, 2004, p.357). Furthermore, Kurtzer-White and Luterman surmise that at the point of diagnosis, parents can experience anger, which is strongly associated with the fear of "violated expectations and a loss of control" (Kurtzer-White & Luterman, 2003, p.234). They suggest this may sometimes be directed at the clinician. Thus, effective communication can be a challenging task in an emotionally charged context.

As well as highlighting communication as a critical component of parent-professional interaction, parents also consistently highlighted the need for clinicians to be "well trained in the emotional impact of the news" (Luterman & Kurtzer-White, 1999, p.16, 17). One article highlighted that clinicians "have been shown to lack both confidence and skill" in communicating the diagnosis, and found that "50% of parents expressed dissatisfaction with the process of the breaking of bad news" (Gibley, 2010, p. 265). Parents across many studies emphasised the need for professionals to have empathetic listening skills and provide emotional support during the acute vulnerability of the diagnostic period (Russ et al, 2004; Luterman, 1999; Minchom et al, 2003; English & Archbold, 2014). In the voice of one parent in Luterman and Kurtzer-White's study, the clinician needs to "be prepared to deal with the emotional ramifications of the news they deliver" (1999, p.17). Thus, an audiologist needs to be an empathetic counsellor, a competent practitioner, and an adept communicator (Russ et al, 2004). In recognition of these requirements, Russ et al argue that "the concept of specialised training in counselling is needed" for both audiologists and the wider team of clinicians to efficaciously support parents during a period of acute vulnerability (Russ et al, 2004, p.357).

Finally, the power-dynamic between the parent and professional can be critically important in the decision making process. Kurtzer-White and Luterman highlight that parents who feel particularly overwhelmed, confused, inadequate, and insecure, sometimes cope by relinquishing decision to the professionals, entreating them to choose the correct options for the child (2003). However, this abdication of responsibility has the danger of creating dependency problems and disempowering the parent (Kurtzer-White & Luterman, 2003). DesGeorges, who is both a parent of a deaf child and a director of a family-support organisation, calls for a balanced power-dynamic (2003). She stresses that professional practice should not only be family-centred, it should empower the parents as they meet the needs of their child (2003). She argues strongly that the parent-professional relationship should be a collaborative partnership which is constituted by "mutual respect", "shared planning and decision making" and "joint evaluation of progress" (DesGeorges, 2003, p.93; Young et al, 2009). This empowerment yields a tremendous impact, as parental involvement is recognised as one of the determining factors influencing the effectiveness of the intervention, and the child's subsequent development (Desjardin, 2003; Yucel et al, 2008; Young et al, 2009). DesGeorges (2003), as well as Young et al (2004), advocate that this parent-professional collaboration should extend beyond individual case management, to a corporate level, as parents should be represented in the macro decision making process, and be offered the opportunity to evaluate and influence the direction of intervention programmes and services.

2.8 Five Gaps

The publications of Kurtzer-White and Luterman (2003; 1999), Young and Tattersall (2007), Russ et al (2004), and Fitzpatrick et al (2007) have been highly influential in shaping the academic discussion regarding parental coping with an early diagnosis of their child's

hearing loss. These authors transformed the trajectory of thought on the subject, replacing a pattern of inattention with an in-depth analysis. They present a comprehensive examination of a complex subject. However, five significant gaps are evident, not only in these seminal works, but also within the wider body of literature.

Firstly, there is a pattern of methodological ambiguity within the wider body of research. The researcher conduced a careful methodological analysis of the top 39 articles within this literature review (which each had 3 or more citations). This was particularly difficult to compose due to vague research designs. Not one of the 39 articles (0%) defined their overarching research paradigm (positivism/ post-positivism/ constructivism etc.). No article (0%) explicitly defined their attendant strategy of inquiry. However, the researcher deduced (from descriptions of the analysis of data) that 5 of the 39 articles (signifying 13%) could possibly be categorised as either

- Phenomenology (Hardonk et al, 2011)
- Ethnography (Young, 1999)
- Grounded theory (Fitzpatrick et al, 2008; Fitzpatrick et al, 2007)
- Interpretive phenomenology/ discourse analysis (Matthijs et al, 2012).

Conversely, even these categorisations are disputable. For example, while Fitzpatrick et al (2008, 2007) described their use of Straussian grounded theory methods in data collection and analysis, they do not present their article as a grounded theory study, nor do they conclude their article with a grounded theory concept (which is a hallmark of Straussian grounded theory). Therefore, the author's categorisation of the implicit strategies of inquiries underlying these 5 articles is indeterminate, thus reinforcing the ambiguity of the attendant research designs. Ultimately, while the practical elements of the methodology (research tools and sampling) were

habitually outlined, the overarching research design (in particular the paradigm and strategy of inquiry) was consistently vague.

Secondly, there is a pattern of lack of appropriate methodological categorisation. Although, the methodological analysis revealed that significantly more clarity was afforded to the practical aspects of the research design, appropriate classifications were often lacking. While the 39 articles habitually described their approaches to sampling, only 10 articles (which represents 25%) provided explicit classifications. These classifications included:

- Purposeful sampling (Young & Tattersall, 2007; Young & Tattersall, 2005; Tattersall & Young, 2006; Fitzpatrick et al, 2007; Fitzpatrick et al 2008, Matthijs et al, 2012)
- Random sampling (Mohd Khairi et al, 2011; Yucel et al, 2008; Van Der Ploeg, 2008)
- Intentional sampling (Hardonk et al, 2011)

Furthermore, although clearly stated, a number of these classifications were imprecise. For example, in Fitzpatrick et al's study published in 2008, it is unclear if the authors are employing the term "purposeful" as an adjective or as a categorisation. Furthermore, in their earlier study, while Fitzpatrick et al (2007) clearly classify a purposeful sample, their attendant explanation calls this classification into question; their description of the analysis of data guiding their search for new data, suggests a sampling that is theoretical rather than purposeful. This alternative classification (theoretical sampling) would have been more consistent with the Straussian grounded theory methods outlined in their article. Therefore, Fitzpatrick et al (2007) appear to present an inaccurate classification of their sampling. Likewise, Yucel et al (2008) identify a random sampling approach to their research, but their description suggests it could more accurately be defined as purposive (Yucel et al, 2008).

Thirdly, a methodological analysis reveals that the parent's voice is afforded a limited influence. While 15 studies[11] (with three or more citations) are specifically underlined by an inductive and qualitative/mixed methods approach (thus eliciting an emic perspective), no author (among the top 39 articles) appeared to fashion a research design requiring the analysis of data to be presented back to parents at a later stage of the research[12]. The absence of this methodological directive is a short-falling as the voice of parents can be lost in the analysis of data. The author's conclusions could be filtered through their personal axiology, and reshaped to such an extent that parents themselves may not feel the publication is an accurate representation of their experience. In contrast, an invitation to respond to the analysis of data would provide parents with an opportunity to confirm or contradict the analysis, and allow them to affect the composition of subsequent recommendations. The voice of the parent would then permeate the research with more integrity.

Fourthly, there is a conceptual gap in the literature. While the qualitative articles in the literature review (and in particular the four seminal publications) draw out significant themes of parental experience in a descriptive capacity, they do not assemble all the different components together to present a cohesive framework. Nor do they present a theory conceptualising parental coping with an early diagnosis of this child's hearing loss. This seems to represent a gap in the literature. Only one article in the entire literature review (authored by Hardonk et al, 2011a) addresses this gap. Taking a conceptual perspective Hardonk et al (2011a) propose five trajectory phases which punctuate the parental experience of receiving an early diagnosis. This framework will be analysed at a later point of this thesis. The low citation

[11] The 15 studies (with three of more citations in the literature review) are as follows: Manguson & Herglis, 1999; Young & Tattersall, 2007; Luterman & Kurtzer-White, 1999; Herglis & Herglis, 2000; Russ et al, 2004; Fitzpatrick et al, 2007; Young & Tattersall, 2005; Fitzpatrick et al, 2008; Tattersall & Young, 2006; McCracken et al 2008; Young, 1999; Gibley, 2010; Minchom et al, 2003; Hardonk et al, 2007; Matthijs et al, 2012.

[12] Only one article in this literature review, authored by Kelly and Bibby, 2008, presented the research findings to participants, requesting their feedback and assessment. This study ensured the voice of the parent permeated and validated the study (Kelly & Bibby, 2008). However, with an impact factor of 0 (according to Scopus), this article was ranked 53 in the citation analysis.

analysis of this article appears to be indicative of the inattention the theoretical framework has received in the academic community, thus corroborating the assertion that conceptualisation is neglected.

Finally, there is a geographical gap in the literature. The studies embedded in this literature review arise from a host of countries including the USA, UK, Canada, Sweden, Belgium, Scandinavia, Germany, Austria, Poland, Turkey, Israel, Malaysia and Australia. However, there is a dearth of Irish studies researching the psychological impact of an early diagnosis of hearing loss within a specifically Irish context. At the point of writing this literature review, there appeared to be only two published studies related to the nationwide implementation of UNHS in Ireland: the NARG Report (2011) and O'Connor et al's article (2013). The NARG Report (cited in the Introduction Chapter) specifically elicits the views of parents who experienced a later diagnosis of hearing loss, not an earlier diagnosis (2011). It forms the argument for introducing UNHS into Ireland, but does not follow the families who experienced its implementation. The article composed by O'Connor et al, consists of a numerical and statistical quantification of the first phase of neonatal hearing screening in the Health Services Executive (HSE) South in Ireland (2013). It does not encompass an exploration of family coping and adjustment. Thus, while both these studies are valuable in their own right, neither of them are specifically centred on the subject of parental coping with an early diagnosis of their child's hearing loss.

2.9 Conclusion

This study will endeavour to address these five gaps. It is specifically rooted in an Irish context, exploring the subject of parental coping in a conceptual capacity. The researcher will endeavour to incorporate the voice of the parent into all stages of the collected research,

affording them the opportunity to respond to the analysis of data and affect the subsequent recommendations. Furthermore, a comprehensive research design will structure the entire study and form an important part of its composition. Each methodological component of this study will be debated and defined to ensure a robust and comprehensive construction. The following two chapters will be specifically devoted to this methodological endeavour, exhaustively assembling the philosophical framework of this study and defining the strategy of inquiry.

3. Philosophical Foundations

3.1 Introduction

Metaphysical assumptions permeate the process of investigation from conception to conclusion (Grix, 2002). A research study is underlined by an assumption of the nature of the studied reality, a presupposition of the investigator's capacity to perceive and analyse reality, and an implicit assertion of the extent to which conclusions can be generalised and applied to reality. These issues are metaphysical in nature, meaning they relate to the philosophical questions of being and knowing. Self-actualised research recognises the extent to which these metaphysical assumptions permeate the character and conduct of investigation, and strives to make them explicit to ensure academic integrity and transparency (Creswell, 2007; Grix, 2002). This endeavour epitomises the aspiration of this chapter. Significantly, this undertaking is not only an academic pursuit, but also a deeply personal disclosure, as the resulting metaphysical demarcation unveils both the intellectual and personal conviction of the researcher. The process of arriving at the concluding philosophical conviction of soft post-positivism/ critical realism is explored in depth in this chapter.

3.2 Defining Terms

Within the specific context of academic research, philosophical considerations are multifarious. They consist of the four-dimensions of ontology, epistemology, axiology and methodology. Before embarking on a critical analysis of these metaphysical concepts, it is crucial to briefly explain each term to ensure clarity and lucidity. Consequently, the following section provides a succinct summary of the terms.

3.2.1 Ontology

The philosophical term ontology relates to the nature of reality. While there are countless ontological positions, the following three are particularly germane to academic research.

- **Naïve realism** advocates an objectivist perspective. It insists that reality exists apart from, and independently of the observer, and consists of immutable laws which can be impartially apprehended (Guba & Lincoln, 1994).
- **Relativism** represents the (opposite) subjectivist position. It asserts that what we call reality is mediated by observer's perceptions and interpretations, to such an extent that reality cannot exist apart from, or independently of, the observer (Grix, 2010; Guba & Lincoln, 1994). Reality is therefore constructed differently by different individuals to render multiple subjective realities (Grix, 2010).
- **Critical realism** signifies a middle-ground. While affirming the existence of one shared, external reality which exists independently of the researcher, it is nevertheless filtered through the perspective of the observer. Consequently, while perceptions correspond to an external reality, they are subject to human interpretation and fallibility.

3.2.2 Axiology

Axiology is concerned with the extent to which the researcher impacts the research. It is interconnected with ontology, as it questions the extent to which the observer's presence, values, and expectations, affects their perception of reality, and the manner in which they acquire knowledge. The following three axiological positions recur in academic research:

- Research can be value-free (associated with a naïve realism)
- The researcher's values influence the research (associated with critical realism)
- All research is inescapably value-laden (associated with relativism)

3.2.3 Epistemology

Epistemology is concerned with the "origin, nature and limitations of human knowledge" (Grix, 2001, p. 36). It questions how one acquires knowledge of this reality. John Frame identified the following three overarching approaches to epistemology which surface throughout the history of philosophy (2008; 1987).

- **Rationalism** encapsulates the pursuit of knowledge through deductive reasoning and logic (Frame, 1987, Markie, 2013). This underlines the discipline of mathematics.
- **Empiricism** encompasses the pursuit of knowledge through sense data, particularly in the form of empirical testing (Frame, 1987). This is manifested in scientific experimentation.
- **Subjectivism** signifies the pursuit of knowledge through the study of subjective experiences, with a focus on investigating "the lived-through meanings and the subjective performances that subtend human situations" (Wertz, 2005, p.168). This epistemology underlines many humanity subjects.

Significantly, while these epistemological traditions are certainly distinctive, the researcher can rarely hold to one exclusively, in complete isolation from the others (John Frame, 1987).

3.2.4 Methodology

Methodology is concerned with the "logic of enquiry" (Grix, 2001, p. 137). It assesses how the study should be executed, investigates the potential techniques, methods, and research procedures, and defends the rationale for selecting a certain approach (Grix, 2001, p.36). Methodology encompasses a number of polarised concepts which are succinctly summarised in table 3.1 on the following page.

Table 3.1 Polarised Methodological Concepts

Qualitative research:	***Quantitative research:***
Research that is concerned with *quality*, seeking a rich, in-depth, descriptive exploration of the inherent meanings, symbols, and characteristics of a subject (Grix, 2010).	Research that is "derived from *quantity*" and pertains to numerical measurements, which can be easily translated into measurements, scales, or analyses (Grix, 2010, loc 2724).
***Inductive approach*:**	***Deductive approach:***
The process of embarking on research in an open-ended, investigative capacity, without a pre-conceived hypothesis. Following data analysis, the researcher generates a concluding hypothesis based on the patterns she has identified.	The sequence of generating a hypothesis from the outset of the study, undertaking data collection and analysis to verify or falsify the hypothesis, and finally confirming, refuting, or adjusting the hypothesis (Trochim, 2006).
Emic perspective:	***Etic perspective:***
The vantage point of individuals within a culture or community (*insiders*) who have first-hand experience of the studied phenomena (Prinz, 2011).	The perspective of an *outsider* who is not a member of the pertaining culture or community, and has not experienced the studied phenomena first hand (Harvard University, 2013).
The objective to understand:	***The objective to explain:***
Seeking to unveil the character, nature, and meanings of the phenomena to explore the nuances of the phenomena and reach a "greater depth of understanding" (Berg, 2001, p.2).	Investigating patterns, regularities, causes, conditions and consequences, of a phenomena with the objective of explanation and prediction (Grix, 2010, Woodward, 2011).

The above dichotomies tend to interconnect with one another. Quantitative, deductive, etic and explanatory approaches can be reciprocal, and are often associated with the objectivism of a realist ontology. Similarly, qualitative, inductive, emic, understanding approaches tend to coincide and are typically equated with the subjectivity of a relativist ontology. However, although these categorisations and ontological associations are archetypical, they are also artificial and represent "a false antithesis" (Grix, 2001, p.34).

The researcher is not restricted in selecting either a qualitative *or* quantitative, etic *or* emic, inductive *or* deductive, explanatory *or* understanding methodology. Many research studies undermine this false dichotomy by efficaciously combining facets of each polarity (Grix, 2001, 2010). For example, the researcher may employ quantitative measurements but

interpret data in a qualitative capacity and vice versa. Consequently, within the confines of consistency, methodological choices are flexible, with many malleable constituent factors.

3.2.5 Strategy of Inquiry

The broad categorisation of methodology is often confused with the more specific term *research methods*. To remove this ambiguity, the alternative term *strategy of inquiry* will be employed throughout this study. There are numerous strategies of inquiry which represent diverse traditions of data collection and analysis (e.g. grounded theory, case studies, action theory, etc.). This subject will receive a concentrated examination in the following chapter.

3.2.6 Research Paradigm

Collectively, when assembled together the selected ontology, epistemology, axiology, and methodology coalesce to form a research paradigm. A paradigm represents a particular research tradition and worldview which is coherent and consistent (Grix, 2001). It denotes, a broad "established academic approach" which acts "as an organising framework for research" and may be applicable to a host of academic disciplines (Grix, 2001, p.138).

Grix argues that the multiplicity of diverse paradigms can be subsumed under the three overarching categories of positivism, post-positivism, and interpretivism (Grix, 2001; Guba & Lincoln, 1994). These three broad paradigms represent "umbrella" categorisations as they each encompass an array of more specific perspectives and movements (Grix, 2010, loc.1860-62). The following table defines these three broad categories of paradigms with reference to their ontological, epistemological, axiological and methodological distinctions:

Table 3.2 Three Alternative Research Paradigms

Overarching Paradigm	Ontology	Axiology	Epistemology	Methodology
Positivism	Naïve realism	Value-free	Generally Empiricism and/or Rationalism	Typically (but not always) quantitative, deductive, etic, explanatory, objectivist
Post-Positivism	Critical realism	Values influence the research	Empiricism, Rationalism and/or Subjectivism	Varied
Interpretivism/ Constructivism	Relativism	All research is value-laden	Generally Subjectivism	Typically (but not always) qualitative, inductive, emic, understanding, subjectivist

As evident in the above table, the three broad paradigms correspond with the aforementioned ontological, axiological, epistemological and methodological stances.

3.3 A Critical Analysis of Competing Paradigms

Having presented the philosophical terms, concepts and frameworks embedded within each of the three alternative paradigms, the researcher will proceed with critical analysis. Each paradigm will be carefully examined with a view to designing the philosophical framework to undergird this study.

3.3.1 The Problem with the Positivist Paradigm

The positivist paradigm is constituted by a naïve realist ontological assertion that reality exists apart from, and independently of the researcher. The associated objectivist axiology infers that the researcher's task is to discover "the facts as they are" and to provide a literal and objective account of the phenomena, which should be impervious to their personal values or beliefs (Schwandt, 1994, p. 125). This ontological and axiological supposition (imbued within

the positivist paradigm) is strongly associated with modernism and embodies the "received view" which "has proved to be the most dominant research paradigm of the past century" particularly its expression and success in the field of natural science (Guba & Lincoln, 1994, p. 110; Grix, 2010, loc.1880-82). However, in 1962, Thomas S. Kuhn (a physicist and philosopher) published the seminal book entitled *The Structure of Scientific Revolutions* (he later published a second edition in 1970) which challenged many of the implicit philosophical assumptions which are indicative of positivism. Kuhn's treatise is renowned as "one of the most influential books of the 20th century" (Naughton, 2012, para 1).

Kuhn undermines the philosophical assumptions embedded within the scientific investigation of his era (1970). He strongly disputed the ontological and axiological supposition that research can be impervious to the researcher**,** asserting that the researcher's influence pervades the research process from design, to execution, to conclusion (Kuhn, 1970). He argued that this is evident in countless ways; even the selection of instrumentation at the outset of a study is indicative of the researcher's influence because "consciously nor not, the decision to employ a particular piece of apparatus and to use it in a particular way carries an assumption that only certain sorts of circumstances will arise" (Kuhn, 1970, loc.1052). Kuhn argued that these "instrumental as well as theoretical expectations…have often played a decisive role in scientific development" (Kuhn, 1970, loc.1052).

Kuhn also argued that the process of researching itself is influenced by the researcher's prior academic experience, "accidents of his investigation", and "his own individual makeup" (Kuhn, 1970, loc.198). The empirical world does not simply present itself to the researcher in terms of her received forms and categories, rather, research can be depicted "as a strenuous and devoted attempt to force nature into the conceptual boxes supplied by professional education" (Kuhn, 1970, loc. 214). Furthermore, methodological directives, taken in isolation, are insufficient to fashion a "substantiated conclusion" but the researcher exercises an interpretive

influence in selecting "what aspects of the complex phenomenon" to study and what "results strike him as particularly relevant" (Kuhn, 1970, loc. 198). Therefore, contrary to the claims of the positivist paradigm, the researcher is not a passive conduit in a research endeavour but exercises considerable influence during each stage of the process.

Kuhn corroborated his assertions by highlighting that the history of scientific inquiry is marked with significant "bodies of belief" which, far from reflecting an accurate depiction of reality, have long been discarded as deficient (Kuhn, 1970, loc. 181-5). He argued that these "out-of-date theories are not in principle unscientific" as they were "produced by the same sorts of methods and held for the same sorts of reasons that now lead to scientific knowledge" (Kuhn, 1970, loc. 181-5). The history of scientific inquiry therefore reveals that representations of reality are not unobtrusively discovered in an unmitigated capacity, but fashioned by an observer and subject to fallibility. Thus, Kuhn proved that there is not an obliterated or "unmediated path" from experimentation to conclusions (Goard, 2011, p.30, 31). Ultimately, Kuhn's ontological and axiological criticisms have undermined the positivist framework to such an extent that he precipitated a paradigm shift in scientific inquiry which gradually underwent a philosophical a transition from positivism to post-positivism. Significantly, Kunh's Structure of Scientific Revolutions is now renowned as "one of the most influential books of the 20th century" (Naughton, 2012, para 1).

3.3.2 The Interpretivist Response

Adherents of the opposite philosophical position of interpretivism (advocating a relativist ontology and subjectivist axiology) embrace Kuhn's criticisms, but derive more radical conclusions. This is clearly epitomised in the worldview of radical-constructivism (which represents an expression of interpretivism). Radical-constructivism asserts that what

we call reality is mediated by human cognition and language to such an extent that we cannot discern if our constructs have any correspondence with an independent reality beyond our cognition (Schwandt, 1994). The researcher cannot appeal to an objective 'real world' as they cannot step outside of their humanity to access an "independent objective world that stands apart from our experience of it" (Schwandt, 1994, p. 127). Consequently, radical-constructivism asserts that rather than the existence of one objective reality or truth, there is a multiplicity of realities and truths which are relative to each individual who experiences and constructs their world differently.

The underlying ontological and axiological position within this philosophical stance is often imbued with political and emancipatory connotations. Many post-modern thinkers (including Derrida, Lacan, Barthes and Foucault) proceed to advocate that language does not directly correlate with reality (Frame, 2008). They assert that "when as ask for the meaning of a word, we get, as a definition, other words. So words refer to other words, not to any objective reality" (Frame, 2008, p.88). As a consequence what we call "'reality' is socially and discursively 'constructed' by human actors" (Grix, 2010, loc.1577-83). Competing discourses vie for "explanatory power", and seek to dominate the consensus view with a meta-narrative or grand-narrative (Ryan, 2006, p.23; Frame 2008). The task of the researcher is therefore to deconstruct these narratives to reveal the power imbalance between the grand narratives of the dominant culture imposing its discourse upon marginalised communities (Frame, 2008). This endeavour carries connotations of an emancipatory ideology, as the researcher exposes how the dominant discourse privileges the interests of the powerful and oppresses the vulnerable (Ryan, 2006). This politicisation of a relativist ontology is adopted by feminist, socialist and other emancipatory causes who seek to challenge the dominant discourses of society (Frame, 2008).

However, there is an inherent difficulty with marrying this emancipatory ideology with the relativist ontology and axiology of radical-constructivism. As nothing can be classified as objectively true or false, inherently right or wrong, ethical or unethical, moral or immoral, within this relativist framework, then the emancipatory ideal is severely undermined (Frame, 2008). If justice is merely a social construct, fashioned by the strong, to subordinate the weak, the struggle of a marginalised group (such as feminists), to transform the dominant discourse of the culture, will not represent a liberation; if the feminist discourse usurps the previous and becomes the prevailing narrative it will succeed the position of power, and impose a new discourse on the culture, which then will be resisted by the smaller narratives of weaker marginalised groups who find it oppressive (Frame, 2008). Thus, the power struggle will continue. The new discourse is not objectively more just than the former, it is only more just by its own subjective definition. Consequently, the crux of the difficulty is that within the relativist framework, there is no meta-narrative that is inherently true, right, or just, there are only competing narratives (reflecting sub-cultures) who compete to define what is true, right and just to serve their own interests (Frame, 2008). Thus, the emancipatory appeal for justice is undermined as any narrative that wields power will be oppressive. Furthermore, the subjectivity of justice leads to a disturbing conclusion. If there is nothing intrinsically just, then there is also nothing intrinsically unjust.

Although strongly associated with the post-modernist era, the relativist ontology and axiology is neither novel nor unique. Relativism can be traced back to the Sophists ("educators in fifth- and forth-century BC Greece") who propagated a relativist ontological position, advocating that "there is no absolute or objective truth, no truth that everyone must acknowledge" (Frame, 2008, p. 73). The Sophists advocated that "reality is what man thinks it is" and held "that there is no objective truth at all, but only truth "for me" and "for you."" (Frame, 2008, p. 76, 73) In Plato's literature, this ontological position is irredeemably

undermined as Socrates accuses that "Sophists themselves are making assertions of fact. If there is no objective truth, then the Sophists' positions are not objectively true" (Frame, 2008, p. 76). Thus Socrates exposes this position as contradictory and self-refuting (Frame, 2008).

3.3.3 The Middle-Ground of Post-Positivism

The post-positivist paradigm represents a middle-ground between the dichotomy of the positivist and interpretivist frameworks. The post-positivist position is defined by a critical realist ontology to such an extent the paradigm is can also be termed critical realism. This ontological stance rejects a relativist depiction of reality, insisting that the empirical world is clearly more than a social construct as it may resist, disrupt our conceptions and cognitive constructs. This is evident in the "unexpected character often stubbornly displayed by nature" as it refuses to bow to our construct if it (Polkinghorne, 2005, p. 4). As Polkinghorne argues

> Far from its behaving like epistemological clay in our pattern-seeking hands, capable of being moulded into any pleasing shape that takes the fancy, the physical world frequently proves highly surprising, resisting our expectations and forcing us to extend, in unanticipated ways, the range of our intellectual understanding (2005, p. 4).

However, the critical realist also rejects the ontological and axiological assertions of naïve realism, emphasising that the reality does not merely present itself in an unmediated capacity to the passive researcher. While depictions of reality correspond to an external world, they are inevitably filtered through the researcher's interpretative perspective. In contrast to the naïve realist position, critical realism insists that reality it is not perfectly apprehensible and claims about the external reality are not immutable. Hence, a realist position is adopted in a critical capacity (*critical realism*) as claims about reality must be subject to critical scrutiny and revision. Consequently, critical realism is a "powerful alternative" to the polarities of relativism

and naïve realism and serves to "bridge the gap between the two extremes" (Grix, 2010, loc.2004-7).

However, this identification of critical realism (and as a consequence post-positivism) as an intermediary position between two polarities is not universally accepted. Denzin and Lincoln (1994) as well as Guba and Lincoln (1994) consider positivism and post-positivism to be correlated to such an extent that the two positions are portrayed as interchangeable entities. Far from being differentiated, they even appear within one category in Denzin and Lincoln's literature; they are represented as the "positivist/postpositivist" position and characterised as employing the narration of "scientific report" (1994, p.13). Lincoln and Denzin criticise the underlying realist ontology which they regard as coercive as it seeks to "legislate one version of truth over another" in an oppressive capacity (2000, p. 8). The constructivist departure from the cannon of realism and objectivity is portrayed as an emancipation "from hearing only the voices of Western Europe, emancipation from generations of silence, emancipation from seeing the world in one colour" (Lincoln and Denzin (referring to Hannah Arendt), 2000, p. 185). Likewise, Guba and Lincoln equate the axiology of positivism and post-positivism, and assert that "in both these paradigms values are specifically excluded; indeed, the paradigm is claimed to be "value free" by virtue of its epistemological posture" (Guba & Lincoln, 1994, p. 114).

However these criticisms are dubious. Firstly, the alleged oppressive nature of realism, disingenuously "exempts" relativism "from its own critique"; the relativist assertion of ontological superiority, over and above a realist ontology, is subject to the same charges of oppression and coercion (Frame, 2008, p. 90). Secondly, as explicated previously, the argument against realism is self-refuting as it amounts to the objective truth that there is no objective truth (Frame, 2008). Thirdly, the overarching criticisms levied at realist stances, fail to adequately account for the distinction between naïve realism and critical realism. Although the critical realist position affirms the existence of an external reality, it digresses from naïve

realism with the acknowledgement that reality cannot be observed apart from the observer. It recognises the researcher's interpretive influence on the research and concedes the impact of context. Fourthly, the axiological criticisms of post-positivism are founded upon a misrepresentation. Unlike positivism, all forms of post-positivism acknowledge the influence of the observer in interpreting what is observed. Thus, each of these (refuted) criticisms are grounded in the mistaken assumption that positivism and post-positivism are essentially interchangeable paradigms operating within the same framework of basic beliefs. They fail not only to take account of this differentiation, but they also fail to recognise the breadth of post-positivist expressions.

3.3.4 Selection and Disclosure

The process of investigating and subsequently selecting the philosophical position to undergird this study is not only an intellectual pursuit, but also a deeply personal disclosure as it exposes the researcher's belief system and personal worldview (Denzin & Lincoln, 1994). Ontologically, the researcher rejects a naïve realist perspective, averting that the external reality does not simply present itself to us in an obliterated capacity in terms of our received categories, conceptions, and depictions of it. The researcher also rejects a relativist ontology as she is convinced that, contrary to the relativist assertions, there is a correspondence (albeit imperfect) between our perception and the existence of an external reality. She also rejects the emphasis on the individual as the focal point of reality (Frame, 2008). Thus, the researcher embraces a critical realist ontology, acknowledging the existence of a reality beyond her conception of it, while affirming the interpretive influence she yields as she studies it. This philosophical affiliation unambiguously locates the researcher within the post-positivist paradigm. Within this philosophical position there are a broad array of epistemological and methodological choices available to the researcher which necessitate further consideration.

3.3.5 Epistemological and Methodological Choices

Within the post-positivist paradigm, the researcher has the freedom to employ (or combine) a rational, empirical, and/or subjectivist epistemology. The process of selection was primarily guided by the purpose of this study, which seeks to understand and conceptualise parents' personal perspective of coping with an early diagnosis of their child's hearing loss. This ambition clearly necessitates a subjectivist epistemology, capable of investigating the subjective meanings, interpretations, and significance that individuals attribute to their experiences.

The purpose of this study was also seminal in directing methodological decisions. The objective to explore parents *own experiences* in their *own words* necessitated a qualitative methodology which can access "the actor's perspective through detailed interviewing" rather than relying on "more remote, inferential empirical materials" (Denzin & Lincoln, 1994, p.5). The researcher's aspiration to explore what *parents themselves prioritise* as critical to this experience, and allow this to guide the research (rather than embarking on the research with priori assumptions or a preconceived hypothesis) guided her selection of an *inductive and emic* methodology. Furthermore, the researcher's ambition to draw out key themes of parent's experiences, analyse them carefully and collate them into a conceptual framework to both *understand* and *explain* the process of coping with an early diagnosis of hearing loss created the further methodological demarcation of (what Webber coined as) *explanatory understanding* (Grix, 2010). Thus, the purpose, subject, and aspiration of this study naturally correlated with a qualitative, emic and inductive methodology with the aim of explanatory understanding. The remaining methodological deliberation of selecting the attendant strategy of inquiry will be addressed in the following chapter to ensure a thorough analysis of this important decision.

3.3.6 Defining and Defending the Research Design

The above process of investigation has cemented post-positivism as the philosophical bedrock of this study. However, as Grix asserted, there is a gradation within all the paradigms which can be adopted in a hard or soft capacity; successive paradigms may overlap with one another as hard proponents of one paradigm meet soft proponents of the other. Due to the subjectivist emphasis within the researcher's epistemological and methodological design, her particular variation of post-positivism may overlap with some expressions of interpretivism. Thus, the selected paradigm of this study can be more accurately classified as soft post-positivism.

The researcher's pursuit of subjectivist inquiry within a post-positivist paradigm may be considered incongruous by constructivist critics. Denzin and Lincoln state that the aim of a post-positivist inquiry is "scientific report" (Denzin and Lincoln, 1994, p.13). Likewise Guba and Lincoln consider that the ambition of post-positivist inquiry is objective explanation "ultimately enabling the prediction and control of phenomena, whether physical or human" (Guba & Lincoln, 1994, p. 113). Similarly, Clark argues that post-positivism "still focuses on rendering complex aspects of human beings researchable, seeking causation, prediction and explanation in the patterns and regularities of life" (Clark, 1998, p.1247). Each of these critics imply that post-positivism is constituted by the restrictive epistemology of empiricism and rationalism which cannot access the human dimension of inquiry. Denzin and Lincoln criticise that methodologically the post-positivist paradigm prizes quantitative research above qualitative, with emphasis on explanation, prediction, and control, as well as the discovery and falsification of theories (Denzin & Lincoln, 1994, p. 5). They correlate the weakness of positivism with post-positivism, and present the two paradigms as interchangeable entities (Denzin and Lincoln, 1994). Consequently, the research design of this study would most likely appear contradictory to these authors.

It is important to acknowledge that the pursuit of a subjectivist epistemology is indeed problematic within a positivist (as distinct from post-positivist) paradigm. Kuhn's arguments highlight the epistemological and methodological limitations of positivist investigation, particularly in its expression in the **"**drastically restricted vision" of the natural sciences (Kuhn, 1970, loc. 509). This reductionist approach, is both a strength and weakness. Kuhn asserted that "by focusing attention upon a small range of relatively esoteric problems, the paradigm forces scientists to investigate some part of the nature in a detail and depth that would otherwise be unimaginable" (Kuhn, 1970, loc. 509). However, Kuhn identified that the difficulty with this refined focus is that it **"**disregards metaphysical questions" and serves to "insulate the community from those socially important problems that are not reducible to the puzzle form, because they cannot be stated in terms of the conceptual and instrumental tools the paradigm supplies" (Kuhn, 1970, loc. 707-713). This criticism corroborates the objection that "in its quest for universal mechanistic rules", positivism portrays an "overly reductionist view of the person" typifying them as objects, and stripping the context of inquiry (Clark, 1998, p.1245; Denzin & Lincoln, 1994).

However, these criticisms are specific to positivism. Unlike the positivist epistemology, post-positivism is not restricted to an empirical and rational epistemology (and related methodologies). While embracing scientific inquiry, post-positivism is not constricted to only engaging in this type of investigation. Polkinghorne explains that "science describes only one dimension of the many-layered reality within which we live" (2005, p. ix). He asserts that

> If you were to ask a scientist, as a scientist, to tell you all that he or she could about music…they would say…"Music is a neural response to the impact of sound waves on the eardrum". Of course that's true, and in its way worth knowing. But it hardly exhausts the mystery of music (Polkinghorne, 2011, recording 11:15).

Because reality is complex and multi-faceted it necessitates multiple dimensions of inquiry, which should incorporate the material world but also transcend it (Polkinghorne, 2005). Thus,

within a post-positivist framework all three dimensions of rational, empirical, and subjectivist inquiry are endorsed in the pursuit of knowledge.

Far from exhibiting a reductionist perspective of humanity, the post-positivist paradigm can engage in the human dimension of inquiry and effectively study the "subjective, social, spiritual and interpretative aspects of the person, their relationships and psychosomatics" (Clark, 1998, p. 1245). This signifies innovative departure from the reductionism and detachment of positivism, both epistemologically and methodologically. The post-positivist researcher who selects a subjectivist epistemology, has a range of quantitative and qualitative methodological tools at their disposal. These can be employed simultaneously or selectively to study "the complexity of the web of life and experience." (Ryan, 2006, p.19). Constructivist criticisms to the contrary reveals a misrepresentation of the post-positivist paradigm.

The alternative of placing a subjectivist epistemology within a relativist ontology (and associated constructivist paradigm) is problematic. Within the constructivist paradigm the "final aim" of research is to "distil a consensus construction that is more informed and sophisticated than any of the predecessor constructions" (Guba & Lincoln, 1994, p. 111). However, the appeal for the final consensus construction to be judged as more informed, sophisticated, or viable than previous constructions is vehemently criticised. This language represents a façade, concealing an appeal to the accuracy of conclusions, as a more faithful portrayal of the phenomena as evident throughout the research process. The discretion of whether a consensus is more or less sophisticated, more or less informed, more or less viable, is in fact an exploration of whether the construct corresponds more or less accurately with that which it is reflecting. This tacit appeal to a correspondence with an external reality, represents an inconsistency for constructivists because the relative ontology asserts that "the human mind freely constructs its ideas without any reference [or correspondence] to an alleged external world" (McGrath, 2010, p. 77). Consequently, if the incongruous reliance on correspondence

is removed as a determining criteria, then there is no grounds for determining if data is more sophisticated, informed or viable. Data is therefore subject "to the charges of solipsism (there are only *my* accounts) and relativism (all accounts are equally good or bad, worthy or unworthy, true or false, and so on)" with the consequential imputation that "there are unquestioned foundations for any interpretation" (Schwandt, 1994, p. 125). The problems incurred by this alternative framework, corroborate the researcher's decision to root her subjectivist inquiry within a post-positivist framework.

3.4 Conclusion: Cognitive Rest

John Frame described the concept of "cognitive rest": after wrestling with the tensions and divergent arguments of philosophical positions, the researcher may eventually reach a satisfactory conclusion (Frame, 1987, loc. 2035). Having wrestled with the above paradigms, in a deeply personal and academic capacity, the researcher has finally reached a sense of clarity, contentment, and commitment with her chosen paradigm. The table below illustrates the details of this philosophical demarcation. It is cautiously depicted as the provisional design, with a view to refining specific details as the research progresses. This progression will be documented in successive chapters. In particular the selection of a strategy of inquiry will receive a concentrated emphasis in the following chapter.

Table 3.3 The Provisional Research Design of this Study

Overarching Paradigm	Ontology	Axiology	Epistemology	Methodology	Strategy of Inquiry
(Soft) Post-Positivism	Critical realism	Values influence the research	Subjectivism	Qualitative, inductive, emic, explanatory understanding	To be determined in Chapter 4

4. Selecting a Strategy of Inquiry

4.1 Introduction: Choosing a Strategy of Inquiry

The deliberation of choosing the optimal strategy of inquiry to craft this research hinged on the question of which tool would best complement the objective of this study. As outlined previously, the author's ambition is to theorise parents' emic experiences of coping with an early diagnosis of their child's hearing loss. With this objective as the determinative criteria, the author selected *grounded theory* as the optimal strategy of inquiry to undertake this study. Grounded theory is particularly appropriate as it was specifically designed to conceptualise emic experiences of participants and generate an astute theory which arises from data analysis. However, grounded theory is a complex choice as it is not a single entity but consists of three prevailing traditions. This chapter will unveil the distinguishing characteristics of each tradition of grounded theory, and justify the researcher's rationale for choosing Straussian grounded theory above the other two alternatives.

4.2 A Brief History of Grounded Theory

Grounded theory is comprised of such exacting precepts that it necessitates a chapter in itself to detail its methodological characteristics and directives. However, before delving into these complex instructions, it is critical to briefly explore the history of grounded theory to understand the context from which it emerged, the significance of its evolution, and the logic of the contentious schisms within this methodology. While it is only possible to provide a succinct summary presently, a more detailed history is featured in Appendix F of this study.

4.2.1 Genesis

Grounded theory was the innovative brainchild of two American Sociologists, Barney G. Glaser and Anselm L. Strauss. The methodology was forged against the backdrop of their disenchantment while undertaking a research endeavour during the 1960's. This four-year study, entitled *Awareness of Dying* (1965), related to interactions between medical staff and terminally ill patients in hospices. During the research process Glaser and Strauss encountered and criticised the "overemphasis" of verifying theories to the detriment of actually generating the theory itself (Glaser & Strauss, 1967; Moore, 2009). They asserted that the twofold process of firstly generating and subsequently verifying a theory should receive equal treatment within social research. However, they observed that "since verification has primacy on the current sociological scene, the desire to generate theory often becomes secondary, if not totally lost, in specific researches" (Glaser & Strauss, 1967, p. 2).

Glaser and Strauss contended that marrying theory construction with social research would produce a robust and astute hypothesis *grounded* in research. As a consequence Glaser and Strauss fashioned a pioneering methodology to address these issues and bridge the "embarrassing gap between theory and empirical research" (Glaser & Strauss, 1967, p. 2). They entitled their innovative methodology *grounded theory* to encapsulate its overarching objective to ground theory in empirical research. Glaser later abbreviated grounded theory as GT (Glaser & Holton, 2004). This acronym will be utilised for the duration of this study.

Glaser and Strauss reiterated that the ambition of *grounded theory* is not verification of a preconceived theory, or capacious description, rather it is unambiguously defined by its exclusive endeavour to *discover* an underlying theory arising from the systematic analysis of data (1967). The researcher arrives at a hypothesis (in the form of a theory) at the conclusion of the research which conceptualises the chief concern of the study. To achieve this objective

Glaser and Strauss designed a number of distinctive and intricate methodological techniques unique to GT, each of which will be explicated in detail in the latter section of this chapter.

GT soon began to transcend the immediate context it was created from. Two years after the publication of the *Awareness of Dying* study (1965), Glaser and Strauss (upon request) published the *Discovery of Grounded Theory* (1967) to illuminate the GT methodology they had designed and employed during their research (Glaser, 2002). This publication was seminal to the development of qualitative research. Charmaz insisted that *The Discovery of Grounded Theory* "made a cutting-edge statement" as it critiqued the prevailing methodological assumptions and pioneered a systematic procedure for qualitative research (2006, p. 5). Glaser and Strauss proved that qualitative analysis could be methodical, rigorous, and structured, which was particularly important at a time when qualitative research was disparaged within the academic arena (Charmaz, 2006). They also demonstrated the compelling logic and potent capacity of qualitative research to generate theories intimately connected with data. Thus, Charmaz confirms that the epistemological challenge embedded within GT "transformed methodological debates and inspired generations of qualitative researchers" (2006, p. 7).

4.2.2 Development and Divergence

As Glaser and Strauss continued to mature GT, their progression precipitated professional and methodological divergence. By 1990 Strauss had forged an academic alliance with Juliet Corbin and together they reconfigured particular features of the original (Classic) GT. Strauss and Corbin revised many of the original precepts and refined the underlying philosophical assumptions (as discussed later in this chapter). Consequently, with this significant transformation Strauss and Corbin fashioned the alternative *Straussian GT* which

they assembled in their book, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (1990).

Glaser disapproved of Strauss and Corbin's reconfiguration of GT. He criticised that "Strauss' book is without conscience, bordering on immorality" (Glaser, 1992, p. 5). He counteracted their publication by writing a contending book titled *Basics of Grounded Theory Analysis: Emergence vs. Forcing* (1992). Glaser deliberately structured his book in the "exact chapter sequence and nomenclature" of Strauss and Corbin's *Basics of Qualitative Research* (1990) to specifically enable the reader to "follow the correlation and divergence" between both books (Glaser, 1992, p. 10). Glaser believed "it is up to me to write a cogent, clear correction to set researchers using grounded theory on a correct path" to combat the "wrong ideas", "errors" and "misconceptions" that Strauss and Corbin's book was propagating (Glaser, 1992, p. 3). Thus, Glaser described his publication as "a corrected version of Strauss' book" and he saw himself as the defender of the original GT (Glaser, 1992, p. 3).

In successive years, Strauss, Corbin and Glaser continued to develop their diverging positions. Strauss and Corbin produced further publications (1994; 1998; 2004), while Glaser proceeded to publish copious books and articles defending and developing the original conception of GT, later identified as *Classic* GT (1991, 1998, 2001, 2005). However, the schism did not remain within the dual confines of Classic versus Straussian GT. An alumni doctoral student from the sociology department of University of California San Francisco (UCSF), Kathy Charmaz, engaged the academic debate and intrepidly fashioned a third variation of GT. Thus, she forged a new chapter within the history of GT.

Charmaz refashioned the original tenets of GT by translating them into contemporary research paradigms which had evolved significantly since the conception of GT four decades previously (Charmaz, 2006). She departed significantly from both Classic and Straussian *GT*,

which will be explicated later in this chapter. In particular she concentrated on interpreting GT within a constructivist paradigm to forge a distinctly Constructivist GT. Thus, Charmaz fashioned a third variation of the GT methodology which she disseminated in a number of publications including *Grounded theory: Objectivist and constructivist methods* (2000); *Constructing grounded theory* (2006); *Constructionism and the grounded theory method* (2008); *Shifting the grounds: Constructivist grounded theory methods* (2009).

Charmaz's rendition of GT provoked an unequivocal response. Glaser responded in his article titled *Constructivist Grounded Theory? (2002*), describing Charmaz's reconstruction as a "misnomer" (2002, p. 1). Glaser rejected many of the underlining principles of the constructivist paradigm and asserted that Charmaz's reconfiguration lacks the distinctive properties inherent within "pure" GT (Glaser, 2002, p. 13). Glaser also criticised that her depiction of GT procedures are "missed, neglected or quashed" (Glaser, 2002, p. 3). He concluded that Charmaz "is misled in thinking that the constructivist vision is in fact GT" at all (Glaser, 2002, para. 40). The details of these differences are explored at length later. However, Glaser's criticisms were directly challenged by Anthony Bryant (2003) who argued that Glaser provides "very little to counter or clarify the arguments put forward by Charmaz" (Bryant, 2003, para. 23). Bryant concluded that while Glaser may have a "certain right" to "feel proprietorial" about his methodology, he nevertheless "has to acknowledge that GTM[13] has outgrown his grasp" as there are other valid interpretations of GT (Bryant, 2003, para. 25).

The disputes over core tenets of GT and have resulted in three dominant and diverging configurations of the GT methodology: Classic, Straussian and Constructivist GT. Therefore the next section will outline the overlapping and distinctive facets of each version in greater

[13] Grounded Theory Methodology

detail in order to ascertain which would be the most appropriate adaptation to undergird this study.

4.3 Points of Convergence

Despite Glaser's protestations, Straussian and Constructivist GT still claim a kinship with the original Classic GT. Indeed these three traditions of GT continue to embrace a number of the original innovative methodological techniques which originated in the *Discovery of Grounded Theory* (1967). Therefore, before launching into an investigation of their distinctions, it is imperative to firstly explicate the shared foundational concepts, pioneered in the original GT publication (1967), which continue to operate as the bedrock for Classic, Straussian and Constructivist GT.

The original textbook of GT (The Discovery of Grounded Theory, 1967) outlined that at the preliminary stages of a study, the researcher should only make choices regarding the initial gathering of data rather than predetermining the entire procedure of data collection from the outset of the study (Glaser & Strauss, 1967). Glaser and Strauss (1967) contended that decisions regarding data collection cannot be entirely prearranged because the analysis of data will reveal the need for more data[14]. As a consequence, the researcher's progressive research sample will be guided by these unfolding identifications rather than predetermined at the outset of the study. Glaser and Strauss (1967) named this evolving process *theoretical sampling* and highlighted that it continues until the point of *saturation*, when the analysis has been exhausted and no new

[14] This becomes evident at a number of stages throughout the research. Firstly, as data are initially coded and categorised, gaps will become evident, thereby identifying the specific need for further evidence in a particular sphere (Glaser & Strauss, 1967). Secondly, during the simultaneous collecting, coding, and analysis of data, unexpected concepts may emerge which change the direction of the study considerably, thereby redirecting the research, and necessitating further data-collection that could not have been anticipated in advance. Finally, as the underlying hypothesis begins to surface, gaps in the emerging theory will become evident to the researcher, who subsequently identifies the specific need for further evidence in a particular sphere.

data are emerging. Significantly, these precepts continue to remain intrinsic to all three variations of GT as they each contend that the research sample cannot be predetermined; instead, it must be a theoretical sample, dynamically led by the emerging theory until the point of saturation.

The original GT methodology (1967) forged a very specific approach to analysing data which they termed the *constant comparison*. As raw data are meticulously analysed line by line, every incident in the data is coded with a conceptual label. These codes are collated into a plethora of categories denoting higher-level concepts. During this process the researcher is constantly engaged in three levels of comparisons (Glaser & Holton, 2004; Holton, 2010):

1) Codes are compared with codes

2) Codes are compared with emerging categories, and

3) Categories are compared with one another

At the latter stages of research, Glaser and Holton (2004; Holton 2010) suggest that comparative analysis encompasses a final dimension (which the authors suggests could be depicted as the fourth tier of the constant comparative technique):

4) The emerging theory is compared with the literature

Glaser and Strauss insisted that this dance of the collection, coding and analysis of data, punctuated by the beat of the constant comparison should "blur and intertwine continually, from the beginning of an investigation to its end" (Glaser & Strauss, 1967, p. 43).The constant comparison was a distinguishing characteristic of the methodology to the extent that GT was also known as the constant comparative method (Glaser & Holton, 2004; Giske & Artinian, 2007; Jones & Alony, 2011). Accordingly, this remains an essential precept in all three factions

of GT as it enables the analyst to proficiently engender a theory that is credible, consistent, and closely integrated with the data (Glaser & Strauss, 1967).

The technique of *memo writing* represents another hallmark of the original GT. As concepts begin to emerge through the process of coding and constant comparison, the researcher reflects on the data by recording memos of her deliberations and conjectures. Recording memos is critical during this entire process as it "provides an immediate illustration for an idea" and serves to develop reflection, ideas, and codes (Glaser and Strauss, 1967, p. 108). Glaser and Strauss (1967) also stipulated that as the researcher begins to write a theory, it is imperative to gather all of the memos pertaining to each category, in order to have a succinct illustration of each concept, which in turn facilitates the theorising process. Furthermore, they delineated that when it comes to the final stages of writing the research into a thesis or journal paper, the successive memos will provide the map for the researcher to articulate the journey of conceptualising the data, wrestling with complications, and eventually fashioning a theory. Thus, memo writing is intrinsic to GT methodology and continues to pervade Classic, Straussian, and Constructivist variations of GT.

The Discovery of Grounded Theory (1967) also distinguished between substantive and formal theory. Glaser and Strauss originally cautioned that the process of generating a GT within a very specific arena yields a limited substantive theory applicable only to this specific field rather than a universal theory (1967). The question of whether or not this theory has wider applicability, for example, parental coping with any trauma or coping in general, represents a leap from substantive (local) to formal (all-inclusive) theory and necessitates a further study. Glaser and Strauss suggested that substantive theory is the bedrock for formal theory and advised that the researcher should focus on generating only one or the other during the course of a study (Glaser & Strauss, 1967). Significantly, Classic, Straussian, and Constructivist GT

continue to operate within this framework and maintain this distinction between substantive and formal theory.

The above precepts (*theoretical sampling, saturation, comparative analysis, memos, and substantive versus formal theory*) signify quintessential characteristics of GT. These features are deeply embedded within the three derivatives of the GT family. As a consequence, Classic, Straussian, and Constructivist GT, retain a strong familial resemblance. Therefore, regardless of which variation of GT will ultimately underline this study, each of these essential procedures will infuse this research.

4.4 Points of Divergence

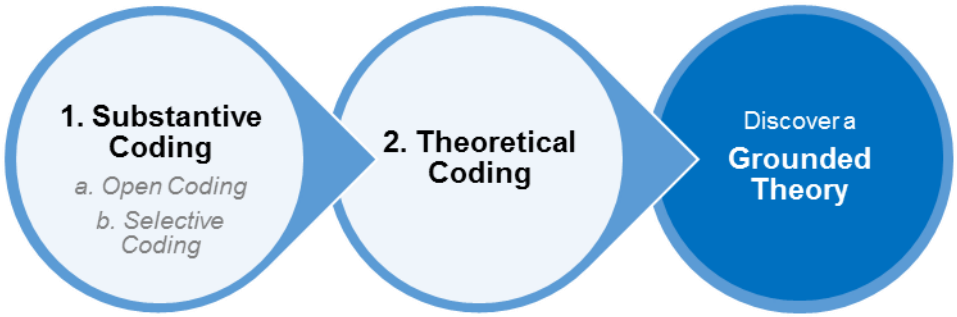
Despite sharing fundamental GT tenets, Classic, Straussian, and Constructivist GT are not homogenous or interchangeable entities. Their incongruity essentially hinges on three principal demarcations: coding procedures, philosophical positions, and the use of literature. From a careful analysis of the literature, these three areas of contention appear to represent the quintessential distinction between the three GT traditions. The remainder of this chapter will concentrate on these three distinguishing areas which demarcate Classic, Straussian and Constructivist GT as diverging methodologies Firstly the coding conventions of Classic, Straussian and Constructivist GT will each be investigated in turn. Secondly, the philosophical assumptions underlying each tradition will each be examined consecutively. Finally the contrasting use of literature will be explored within Classic, Straussian and Constructivist GT.

4.5 Coding Conventions

4.5.1 Classic GT: The Original Coding Convention

While the basic coding procedure of the original Classic GT has essentially remained unchanged, the presentation of it has developed with increasing lucidity. Glaser's recent collaborative work with Judith A. Holton (2004, 2005a, 2005b, 2007), and Holton's own publications (2010), present the coding procedures of Classic GT with a succinct clarity Glaser and Holton propose that the researcher approaches GT data analysis with a series of questions including "What is the main concern being faced by the participants?" and "What accounts for the continual resolving of this concern?" (Glaser & Holton, 2004, para. 48). They asserted that the researcher wrestles with these underlying questions through the process of coding the data, which Holton (2010) cohesively summarised as substantive and theoretical coding. As illustrated by the diagram below, these two stages of coding result in the *discovery* of a GT:

Figure 4.1 The Coding Procedure of Classic GT (Holton, 2010)



These coding stages are imperative to Classic GT as they bind all the concepts of the methodology together and undergird the entire research process from conception to conclusion (Glaser & Holton, 2004; Holton 2010). This concise framework for depicting Classic Grounded Theory is described in detail in Table 4.1:

Table 4.1 The Coding Procedure of Classic GT (Holton, 2010)

Stage	Description
Substantive Coding: a) Open Coding	As data are analysed line-by-line, each incident is coded with a key word, which synopsises sections of data (Glaser & Holton, 2004). Coded segments are fragmented from the transcript and grouped conceptually. These groupings (called conceptual categories) are given a conceptual title by the researcher, who forms as many conceptual categories as possible. The researcher engages in the three levels of constant comparison (as outlined previously). As new evidence continues to be gathered, compared, analysed, and categorised, categories become dense and complex and their inter-relationships begin to become apparent. Subsequently, a principal core category will emerge. This must encompass the chief concern of the study, subsume most of the other categories, and be sophisticated enough to account for the complexity and nuances within the data (Giske & Artinian, 2007; Glaser & Holton, 2004; Holton, 2010; Jones & Alony, 2011).
Substantive Coding: b) Selective Coding	The researcher reduces her focus to the core category and the categories which meaningfully relate to it. She engages in *theoretical sampling* and refines the interview questions accordingly (Jones & Alony, 2011). For the purpose of filtering out extraneous material, the collection and coding of incoming data is selectively restricted (or *delimited*) to focus exclusively on relevant data pertaining to the select categories (Holton, 2010). As the researcher saturates these categories, the core category will become increasingly dense and its theoretical relationships with other relevant categories will become apparent. Subsequently, the researcher integrates (or *reduces*) the categories into higher-level substantive concepts to reach a higher level of conceptualisation (Giske & Artinian, 2007; Glaser & Holton, 2004; Holton, 2010; Jones & Alony, 2011).
Theoretical Coding	Theoretical coding comprises the final level of abstraction, as the researcher conceptualises the inter-relationships of the substantive concepts to generate the pertinent hypothesis. This gives rise to an emerging grounded theory that can "account for the relationships between the concepts thereby explaining the latent pattern of social behaviour" (Holton, 2010, para. 1). Glaser insists on *trusting in emergence* of a theory at this point in the research (Glaser, 1992). Literature should be employed at this stage to compare with the GT. Conceptual mapping may also be utilised to facilitate this process (Giske & Artinian, 2007). Theoretical sorting of memos is crucial to retrospectively convey the progressive formulation of the theory in writing (Giske & Artinian, 2007; Holton, 2010; Glaser & Holton, 2004; Jones & Alony, 2011).

The Classic GT coding procedure is underlined by the principle of the natural *emergence* of a theory to be *discovered* from the content of the data. Glaser insisted that while employing the coding procedure, the researcher should patiently "trust that emergence will occur and it does" (Glaser, 1992, p. 3-4; Glaser & Holton, 2004). Glaser conceded that as analysts are human, they inevitably have a natural tendency to unintentionally influence the research with personal biases or interpretations (Glaser, 2002). However, he argued that if the researcher carefully undertakes the coding procedures, rigorously employs the constant comparison technique, abstains from literature, and collects a large breadth of data from many different sources, the totality of these precepts will "correct for bias," diminish the effects of the researcher's personal input, and uncover the underlying "latent patterns" of the phenomena (Glaser, 2002, para. 24). Thus, Glaser argued that this will ultimately "make the data objective" (Glaser, 2002, para. 24).

Despite his clarity with regard to methodological directives, Glaser was ambivalent about what research paradigm Classic GT corresponds to. However, Charmaz (2006), Bryant (2002), Jones and Alony (2011), and Madill et al. (2000) highlighted the implicit positivist assumptions imbued within the pursuit of objectivity and the assertions of the researcher's unobtrusive *discovery* of a latent grounded theory within the content of collected data. Subsequently, these authors stress the connotations of a naïve realist ontology within Classic GT. They contend that Classic GT represents a "soft positivism" which proposes that that research entails "a process of revealing or discovering pre-existing phenomena and the relationship between them" (Madill et al., 2000, p. 4). This is the subject of much criticism, which will be examined later.

A number of authors have questioned the assertions of objectivity claimed by the proponents of the Classic GT coding procedure. Urquhart (2002) insisted that the process of

coding is inevitably "subjective" as the analyst collects, codes, conceptualises, and collates the data according to his or her personal discretion (p. 272). The subjectivity of this process is inevitable as two researchers coding the same interview transcripts inexorably engender different conceptual categories (Madill et al., 2000). Moreover, the researcher's influence permeates every stage of the research, from choices of data collection at the genesis of a study, to discretionary conceptualisation at the conclusion. Thus, rather than unobtrusively or neutrally *discovering* an *emergent* hypothesis, the analyst inevitably has an implicit interpretative influence in the entire process of generating a GT. Therefore, Classic GT can be critiqued as an inconsistent methodology as it employs an interpretivist coding procedure within an objectivist, positivist paradigm (Bryant, 2002, Jones & Alony, 2011, Kelle, 2005).

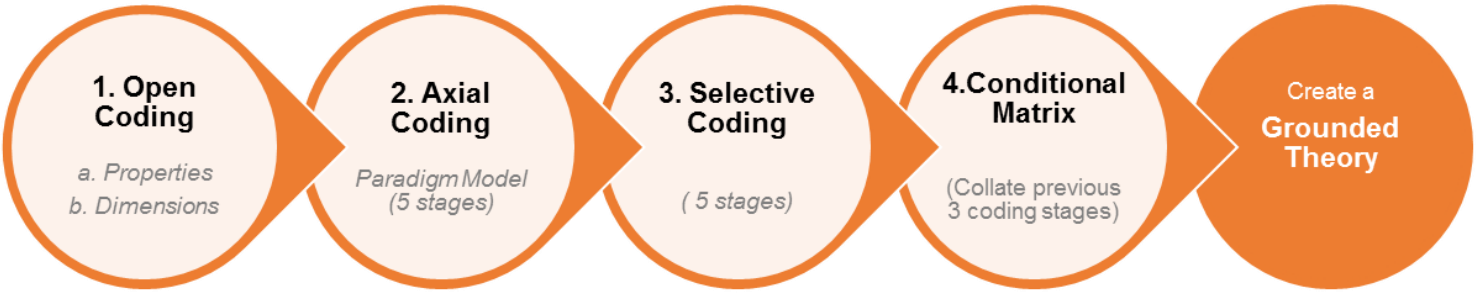
4.5.2 Straussian GT: Coding with Structure

Straussian and Constructivist GT forged divergent philosophical positions. While Glaser avowed that we *discover* a theory within the data, Strauss and Corbin proposed that "we *create* theory out of data" and Charmaz asserted that "we *construct* our grounded theories" (Glaser 1992, Strauss & Corbin, 1998, p. 56; Charmaz, 2006, p. 10). The philosophical nuances of these confutations, as well as Glaser's defence, will be explicated later. Ultimately, the debate of whether a GT is *discovered*, *created,* or *constructed* directly impacted the reconfiguration of coding procedures which reflect these philosophical distinctions.

Strauss and Corbin devised a highly systematic and rigorous coding structure to *create* (rather than to *discover*) a rigorous theory which closely corresponds to the data (Strauss & Corbin, 1990, 1994, 1998). Strauss and Corbin classified four coding stages but qualified that the dividing line between each of the successive phases is somewhat artificial as the researcher constantly moves back and forth between them in consecutive coding sessions (1990).

Significantly, this reformation of GT was so distinctive that it became known as Straussian GT. Their framework is illustrated in the diagram below.

Figure 4.2 The Coding Procedure of Straussian GT (Strauss & Corbin, 1990)



Strauss and Corbin's robust coding procedure largely followed the same sequential progression as Glaser's, but is far more meticulous and specified. They argued that their more specific and complex coding strategies were beneficial for a number reasons. Firstly, Strauss and Corbin elucidated that they were "designed to enhance the effectiveness of this methodology" (Strauss & Corbin, 1994, p. 273). Secondly, Strauss and Corbin conceded that their assiduous coding process may appear complicated, but they argued that this is appropriate because human life is complicated (Strauss & Corbin, 1990). Furthermore, Strauss and Corbin explicated that the volume and precision of their specific coding directives were not intended to confuse the novice researcher. To the contrary, they were specifically designed to "spell out the procedures and techniques" in meticulous "step-by-step fashion" to assist "persons who are about to embark upon their first qualitative analysis project" (Strauss & Corbin, 1990, p. 8). Thus, their more specific coding directives were written for the purpose of enhancement and clarity, rather than confusion. The detailed coding process advocated by Strauss and Corbin (1990) is summarised in Table 4.2.

Table 4.2 The Coding Procedure of Straussian GT (Strauss & Corbin, 1990)

Stage	Description
Open Coding	The researcher begins data analysis by openly coding segments of data with conceptual labels to denote the concept they represent. Through questioning and the constant comparative method, these concepts are grouped into corresponding categories. During open coding, as categories become increasingly dense, the researcher may develop sub-categories. Furthermore, categories may also be subsumed under increasingly abstract, higher-order categories (Strauss & Corbin, 1990, p. 61). **a. Properties of each category** As each category is developed and saturated, the range of properties (features or characteristics) within each category is demarcated (Strauss & Corbin, 1990). **b. Dimensions of each category** Strauss and Corbin specify that properties pertaining to a category are scrutinised in terms of the category's *dimensional ranges*, for example, the range of frequency (often/never), the range of intensity (high/low), the range of degree(more/less), the range of duration (long/short),or any other dimensional ranges which are evident in data analysis (1990, p. 72). Subsequently, properties are located (or *dimensionalised*) along a continuum (called a *dimensional continuum)* thus giving each category a complex *dimensional profile* (Strauss & Corbin, 1990, p. 70).
Axial Coding	Axial coding represents the process of forging links between a category and its emerging sub-categories. They are connected through a very specific set of relationships outlined in the paradigm model. **Paradigm Model** The paradigm model demarcates five sub-categories within every category: *a) causal conditions, b) context, c) intervening conditions, d) action/interactional strategies* and *e) consequences.* Each of these sub-categories has properties and dimensions. They are linked to the overarching category through the relationship specified in their title. This procedure reconfigures some previous standalone categories and refashions them as sub-categories to a higher-level conceptual category. Several overarching categories emerge through this process. They grow in density and precision and mature beyond their aforementioned properties and dimensions (Strauss & Corbin, 1990).

Selective Coding	Selective coding encapsulates the process of integrating the categories with a higher level of abstraction, to fashion a GT (Strauss & Corbin, 1990). As categories become dense, rich, and precise, their inter-relationships with one another become apparent. Subsequently, one dominant *core category* is selected which is broad and abstract enough to integrate the other categories and to cement the components of the phenomena (Strauss & Corbin, 1990). Once the core category is selected, the researcher engages in five crucial steps (not necessarily in sequential order) to nurture the emerging concepts and engender "a picture of reality that is conceptual, comprehensible, and above all grounded" (Strauss & Corbin, 1990, p. 117). **a. Story line** The researcher presents a "general descriptive overview" of the core phenomenon of the study; this descriptive story should be limited to a few sentences (Strauss & Corbin, 1990, p. 119). The researcher should relate the storyline of the study in analytical terms, delineating the core category. **b. Relating subsidiary categories around the core category with a paradigm** The researcher employs the paradigm model to establish the relationship between the *core category* and its newly defined *subsidiary categories*. This ordering of a hierarchy of concepts will begin to yield an overarching theory. As Strauss and Corbin explicate, it takes the form of: "A (conditions) leads to B (phenomenon), which leads to C (context), which leads to D (action/interaction, including strategies), which leads to E (consequences)" (Strauss & Corbin, 1990, p. 125). **c. Relating categories at a dimensional level** The properties and dimensions within the *core category* will also be established. The *subsidiary categories* will be grouped and located "along the dimensional ranges of their properties in accordance with discovered patterns" (Strauss & Corbin, 1990, p. 125). This occurs in tandem with the previous stage. **d. Validating their relationships against data** The emerging theory will be considered provisional until it is validated against the collected data to ensure that it is indisputably grounded in the collected material. **e. Filling in categories that may need further refinement** If there are any remaining "missing details" in the categories, the researcher employs theoretical sampling to fill in the gaps and ensure *conceptual density* (Strauss & Corbin, 1990, p. 141).

Conditional Matrix	The conditional matrix is not a fourth level of coding analysis; it is a "framework that summarises and integrates" the previous three levels of coding (Strauss & Corbin, 1990, p. 158–159). The matrix was designed as an "analytic aid" to assist the researcher in identifying the breadth of determining conditions and consequences related to the subject of study (Strauss & Corbin, 1990, p. 158). Strauss and Corbin specify that the matrix encompasses the following eight levels of influence which range from a micro to a macro scale (1990, p. 163),: 1) *Action Pertaining to a Phenomenon* 2) *Interaction* 3) *Group, Individual, Collective* 4) *Sub-Organisational, Sub-institutional Level;* 5) *Organisational and Institutional Level;* 6) *Community;* 7) *National* 8) *International* The breadth of these successive levels ranges from the specific individual incidents to the general national/international scale (Strauss & Corbin, 1990). The researcher utilises the matrix by tracing a specific incident within the studied phenomenon through the successive levels of the matrix in order to ascertain the *conditional path* of the incident. This will help the researcher identify the significant conditions activating the phenomena, and/or the consequences arising from it. For example, the researcher takes a specific incident, such as a parent's experience of receiving an early diagnosis of their child's hearing loss with no after-care family support, and traces this incident through the matrix levels to ascertain the cause, the determining conditions, the manner in which conditions were manifested, and the resultant consequences (Strauss & Corbin, 1990). This may lead the researcher to the national level of the matrix to consider the government's budgetary cut backs in health care.

Strauss and Corbin's fastidious coding structure was criticised by both Glaser and Charmaz. Glaser (1992) contended that Strauss "misconceives our conceptions of grounded theory to an extreme degree, even destructive degree" (p. 3). In particular, Glaser contested the complicated coding instructions and protested that the researcher is effectively "forcing" the data into "preconceived" concepts in order to coerce a theory (Glaser, 1992, p. 3-4). He asserted

that this serves to “interrupt the true emergence” of a theory and, as a consequence, the “true nature of the data is lost forever” (Glaser, 1992, p. 4). Similarly, Charmaz criticised that the Straussian GT encompasses an excessive “maze of techniques” (Charmaz, 2000, p. 512). She argued that Strauss and Corbin transformed the “original flexible” coding guidelines into “immutable rules” which she characterised as positivist, rigid, narrow, and overly complicated (Charmaz, 2000). Charmaz asserted that axial coding in particular results in “awkward scientific terms and clumsy categories” which detract from participants’ experiences and obfuscates analysis with excessive jargon (Charmaz, 2000, p. 525). She also undermined Straussian conceptual diagrams and maps, criticising that they create an “overly complex architecture” that confounds the data and “obscures experience” (Charmaz, 2000, p. 525). Significantly, several contemporary grounded theorists have supported Charmaz’s and Glaser’s criticisms and argued that the “densely codified operation” of Straussian GT is excessive (Goulding, 1999, p. 7).

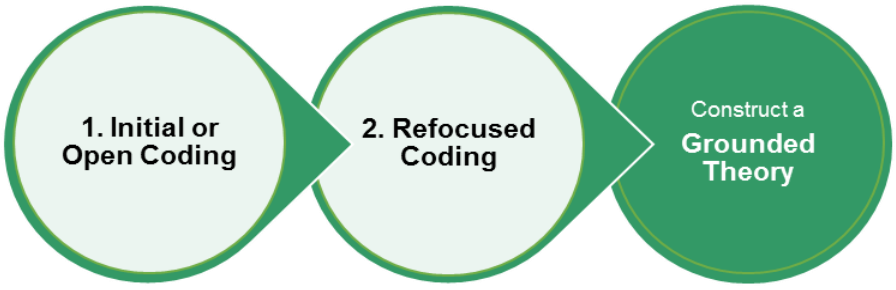
However, Strauss and Corbin defended their coding conception. Before these criticisms were even published, Strauss and Corbin had already clarified that their coding procedure should be applied flexibly and adapted to different circumstances and studies, a directive which Glaser and Charmaz overlooked in their disparaging analysis (Strauss & Corbin, 1990). Furthermore, Strauss and Corbin defended the complexity of their structure with a number of justifications. Firstly, they argued that the prescribed stages are critical to dissipate the researcher’s prejudices and preconceptions which they inevitably bring to, and develop, throughout the study (Strauss & Corbin, 1990). Secondly, they asserted that employing the model will assist, rather than hinder, the researcher, as it will facilitate an exacting and systematic analysis of data, which will allow the researcher to relate concepts in a highly accurate, convincing, and complex capacity (Strauss & Corbin, 1990). Finally, they insisted that this model allows the researcher to build a “rich, tightly woven, explanatory theory that

closely approximates the reality it represents" (Strauss & Corbin, 1990, p. 57). Thus, Strauss and Corbin[15] concluded that "unless you make use of this model your grounded theory analyses will lack density and precision" (Strauss & Corbin, 1990, p. 99).

4.5.3 Constructivist GT: Coding and Contention

Charmaz, a former student of Glaser and Strauss at the University of California, San Francisco disagreed and forged a radical departure from both Straussian and Classic GT. She presented a third adaptation of GT coding, characterised by a distinctly constructivist philosophy. In stark contrast to Straussian GT, Charmaz (2008) resisted a concrete, rule-bound, prescriptive approach to coding, arguing that this stifles and suppresses the researcher's creativity. Instead, she fashioned highly adaptable coding guidelines which endorsed an "imaginative engagement with data" (Charmaz, 2008, p. 168). Charmaz stressed the principle of flexibility in particular, insisting that the analyst must "learn to tolerate ambiguity" and "become receptive to creating emergent categories and strategies" (Charmaz, 2008, p. 168). As illustrated in the diagram below, she proposed a fluid framework, with "at least two stages" to coding (Charmaz, 2008, p. 159):

Figure 4.3 The Coding Procedure of Constructivist GT (Charmaz, 2008)



[15] Straussian GT did not remain a stagnant entity. Following Strauss's death in 1996, Corbin continued to publish, and released a second edition of the Basics of Qualitative Research in 1998, a third edition in 2008, and a fourth edition in 2014. Corbin's successive publications relaxed the formulaic Straussian coding convention, and refashioned the underlying philosophical assumptions (Corbin & Strauss, 2008). However, she was careful to distinguish modifications that Strauss may not have been in accord with (Corbin & Strauss, 2008). Corbin's reformation of Straussian GT moved the methodology in the direction of Constructivist GT.

Charmaz's constructivist coding procedure is punctuated by many generic GT techniques, including memo writing, constant comparisons, theoretical sampling, and saturation (Charmaz, 2008). Significantly, this framework, although vastly more malleable, is analogous with the two-tier structure of Classic GT. Charmaz's framework is elucidated in Table 4.3.

Table 4.3 The Coding Procedure of Constructivist GT (Charmaz, 2008)

Stage	Description
1) Initial or Open Coding	During initial (or open) coding, Charmaz (2008) suggested that by employing Glaser's two key questions, "what is the chief concern of participants*?"* and "how do they resolve this concern?*"* the analyst gleans an invaluable insight in to the collected data (p. 163). She proposed that the analyst codes for actions and potential theoretical cues rather than for themes. Charmaz advised that coding with "gerunds, that is, noun forms of verbs, such as revealing, defining, feeling, or wanting, helps to define what is happening in a fragment" (Charmaz, 2008, p. 164). This exposes "implicit processes, to make connections between codes, and to keep their analyses active and emergent" (Charmaz, 2008, p. 164). Charmaz also proposed the generic GT use of *in vivo* codes, which encompasses utilising the language of the participants as codes (2008).
2) Refocused Coding	The researcher moves into the next stage, *re-focused coding,* by identifying the codes that are recurring or particularly significant in illuminating the studied phenomenon (Charmaz, 2008). These codes typically have "analytic momentum" and are pertinent to "carry the weight of the analysis", which is also described as having the ability to "capacity carry" (Charmaz, 2008, p. 164). The researcher elevates these codes as provisional theoretical categories which subsequently undergo selective or focused coding through the GT techniques of theoretical sampling, theoretical saturation, and memo writing (Charmaz, 2008). Memo writing, in particular, is vital to the process of constructing a theory. Through the medium of memo writing, the researcher can scrutinise the codes and categories, highlight determining conditions, and trace progression and consequences (Charmaz, 2008). The memos may also document "gaps in the data" and help develop conceptual "conjectures" (Charmaz, 2008, p. 166). Thus, writing and sorting memos captures the unfolding process of interpreting the phenomena and constructing a theory.

Charmaz's coding procedure is patently more interpretative, intuitive, and impressionistic than the Classic or Straussian GT (Charmaz, 2006). Charmaz placed a particularly strong emphasis on in-depth, intensive interviewing to purposely yield an intimate exploration of the meanings that participants attribute to their experiences (Charmaz, 2006; Hallberg, 2006). Although these interviews are analysed through the constructivist coding procedure, the analysis rarely culminates into a prognostic or predicative theory presented at the conclusion of the research (Hallberg, 2006). Instead, a Constructivist GT study typically concludes with the researcher's interpretative understanding (rather than explanation) of the studied social process which is presented in the form of a "story" (Hallberg, 2006). Constructivist grounded theorists argue that this narrative approach to GT does not neglect abstraction as it weaves conceptualisation into description (Charmaz, 2006; Hallberg, 2006), particularly as the concluding story encompasses "categories, conditions, conceptual relationships, and consequences" (Hallberg, 2006, p. 147).

Charmaz's reconfiguration of GT was strongly criticised by Glaser. He opposed the constructivist emphasis on descriptive capture, asserting that it "denies and blocks" the "true conceptual nature" of GT (Glaser, 2002, para. 28). Glaser argued that the unequivocal objective of GT is conceptualisation, rather than a faithful description of participants' experiences (Glaser, 2002). Due to Charmaz's emphasis on the latter, Glaser asserted that Charmaz is "misled" in considering her methodology to be a GT as a more accurate classification would be qualitative data analysis (Glaser, 2002, para. 40). In contrast, Strauss and Corbin upheld the value of description and shared a sense of obligation to give their participants a voice and "tell their stories" (Strauss & Corbin, 1994, p. 281). However, Strauss and Corbin implemented this value within a rigorous and robust coding framework which stands in stark contrast with Charmaz's flexible coding guidelines (Strauss & Corbin, 1990). Strauss and Corbin also retained the goal of producing a "conceptually dense" theory at the conclusion of the study

which could accurately account for relationships between concepts constructed from data (Strauss & Corbin, 1994, p. 278). Accordingly, Glaser criticised that the exclusive endeavour to theorise is compromised within Constructivist GT as it promotes narration to the extent that it is "neglecting the fundamental properties of abstraction analysis" (Glaser, 2002, para. 19).

Glaser also rejected Charmaz's underlying constructivist epistemology embedded within her coding procedure. He asserted that the interviewer and interviewee's mutual construction and interpretation of data inappropriately elevates the researcher to the status of co-creator and composer of the story (Glaser, 2002). Glaser argued that this diminishes, rather than augments, the participant's perception of a phenomenon, as it permits his or her experience to be recast by the researcher (Glaser, 2002). He insisted that this "unwarranted intrusion of the researcher" represents a gross violation of GT as it effectively renders the "researcher's interactive impact on data more important than the participants" (Glaser, 2002, para. 8, 20). Glaser avowed that the participant's perspective should always be paramount and should always correct and refine the researcher's abstractions. As a consequence, he asserted that the researcher should "take great pains not to intrude their own views in the data" (Glaser, 2002, para. 14). However, Charmaz defended her position, asserting that it is impossible for the researcher to forge an unobtrusive relationship with social research as "we are part of the world we study and the data we collect" (Charmaz, 2006, p. 10). Ultimately, Glaser and Charmaz's dispute hinged on axiological differences: Glaser presupposed a neutral researcher with an unobtrusive impact on data while Charmaz emphasised the inescapable interactive impact of the researcher on data. These opposing philosophical positions (which will be analysed in the following section) are tangibly manifested in contending frameworks and criticisms of coding and data analysis.

The three factions of GT encapsulate distinct coding structures. The Classic framework retains and refines the original GT coding procedure which was designed to *discover* an *emergent* theory through systematic analysis of data (Glaser & Holton, 2004; Glaser & Strauss,

1967; Holton, 2010). Straussian GT embodies a more rigorous and robust coding structure which was forged to *create* (rather than *discover*) a theory which closely apprehends the data (Strauss & Corbin, 1990). Constructivist GT encapsulates a more impressionistic coding procedure which was fashioned to *construct* a conceptual interpretation (rather than exact apprehension) of the phenomena (Charmaz, 2006, 2008). Thus, the selection of one of these distinctive structures to undergird this study, will have "an important impact in the direction and execution of the primary research" (Jones and Alnoy, 2011, p. 99).

The deliberation of choosing the most appropriate coding strategy will be evaluated at the conclusion of this chapter. This arbitration is specifically delayed for the purpose of assessing each variation of GT in its entirety, rather than on the basis of its coding procedures alone. The following section will address the question of paradigms, which represents the second profound distinction differentiating the three factions of GT. Significantly, these two major distinctions (coding strategies and paradigms) are inextricably linked, as the coding contentions arise from opposing philosophical positions embedded within competing research paradigms.

4.6 Corresponding Paradigms

There is ample debate in the academic literature as to which paradigm Classic GT best corresponds to. Bryant (2002) and Urquhart (2002) attested that the original GT texts were virtually silent on the questions of epistemology and ontology, which has continued to cloak the philosophical position of Classic GT in ambiguity. Glaser maintained that the methodology itself was "discovered, not invented" and as such he resisted marrying it with a research paradigm, stating that it "stands alone, on its own, as a conceptualising methodology" (Glaser & Holton, 2004, para. 75, 39). Glaser primarily perceived GT to be a research method which

he divorced from philosophical considerations (Urquhart, 2002). He reiterated his position at a conference address, stating "let me be clear. Grounded theory is a general method. It can be used on any data or combination of data" (Glaser cited in Urquhart, 2002, p. 47). As a consequence of Glaser's philosophical abstruseness, Moore (2009) suggested that the covert epistemological assumptions embedded within grounded theory are not clearly articulated or defined, which has resulted in the "misinterpretation and misuse of the method" (p.8).

Charmaz addressed this ambiguity directly. She argued that, despite Glaser's reticence, the original Classic GT appears to be closely correlated with traditional positivism as it implicitly assumes "an objective, external reality, a neutral observer who discovers data, reductionist inquiry of manageable research problems, and objectivist rendering of data" (Charmaz, 2000, p. 510). Charmaz traces Glaser's inclination towards objectivism back to his formative experience as a graduate student at Columbia University, where Glaser was influenced by his rigorous quantitative and positivist training under Paul Lasarsfelt (Charmaz, 2000). As explicated previously a host of academics including, Bryant (2002), Jones & Alony, (2011), and Madill et al (2000), echo Charmaz's assessment. Significantly, even, Strauss, the original co-founder of GT, conceded the positivist nuances embedded within the terminology of *discovering* a pre-existent theory which emerges from "out there" (Strauss and Corbin, 1994, p. 279).

However, Charmaz's assessment is not unanimously accepted. McCann and Clark (2003) argued that Classic GT is demarcated by an implicit post-positivist (rather than positivist) paradigm and underlined with a critical realist (rather than realist) ontology (cited in Moore, 2009). Urquhart (2002) also holds this position, which she attributed to the influence of symbolic interactionism from the inception of GT through the input of Strauss (see Appendix B for an explanation of symbolic interactionism and pragmatism). However, Glaser himself

later resisted this philosophy stating "GT became considered, wrongly, as a symbolic interaction method" (Glaser & Holton, 2004, para. 38). He also bemoaned that at times "grounded theory is considered qualitative, symbolic interaction research" which he depicted as "a kind of takeover" (Glaser 1999, as cited in Urquhart 2001, p. 16). Glaser's explicit rejection of symbolic interactionism, which encompasses a critical realist ontology and is a derivate of a post-positive philosophy, indicates his disassociation of with Strauss' more defined philosophical position. Furthermore, while Charmaz details Strauss' considerable influence in weaving symbolic interactionism into the methodology of Classic GT, she affirms that it is Glaser's "epistemological assumptions" that pervade the underlying philosophy of GT (Charmaz, 2006, p. 7).

Glaser's writing indicates his cognisance of his alleged positivist proclivity (Glaser 2002). Glaser cited Charmaz's classification of his ontological and epistemological position in his article *Constructivist Grounded Theory?* (2002). He directly quoted Charmaz's assertion that Classic GT assumes "an external reality" which is "independent of the observer and the methods used to produce it" (Charmaz, 2000, p. 513 as cited in Glaser 2002, para. 18). In his lengthy citation, Glaser also referenced Charmaz's avowal that Classic GT "follow[s] the canons of objective reportage" and culminates in to an "objective stance" (Charmaz, 2000, p. 513, as cited in Glaser 2002, para. 18). Although Glaser proceeded to unequivocally criticise Charmaz's handling of GT, he did not refute her identification of positivist connotations or challenge her classification of the objectivist ontology and epistemology embedded within Classic GT (Glaser 2002). Instead he responded with a defence of the GT techniques and methodology, contending that they serve to "make the generated theory as objective as humanly possible" (Glaser 2002, para. 19). Thus, while Glaser criticised Charmaz's constructivist paradigm and her subsequent reinterpretation of GT, he refrains from contesting her

classification of Classic GT as implicitly positivist. This reticence may be indicative of his acquiescence.

Charmaz argued that Strauss and Corbin's rendition of Straussian GT is also undergirded with positivist assumptions. To corroborate her assertion, she highlighted the Straussian ontological presupposition of an external and objective reality, as well as the array of meticulous methodological procedures which, she argued, strive towards impartial data collection and verification of data (Charmaz, 2000). Charmaz tempered her assessment with the acknowledgement that Strauss and Corbin's position is more nuanced than that of Glaser, particularly as they recommend the incorporation of the participant's story into the research, and acknowledge that the participant and analyst may not share the same perspective (Charmaz, 2000). Charmaz identified these distinctions (and others) as strands of post-positivism, and traced this disposition back to Strauss' exposure to the philosophy of pragmatism and symbolic interactionism, as a graduate student in the University of Chicago (Charmaz, 2000). Despite Charmaz's acknowledgement of these various influences and nuances, she ultimately asserted that regardless of Glaser and Strauss's divergence, both authors continue to retain a methodology "imbued with positivism with its objectivist underpinnings" (Charmaz, 2000, p. 510). Thus, Charmaz concluded that "both endorse a realist ontology and positivist epistemology, albeit with some sharp differences" (Charmaz, 2000, p. 513).

However, Charmaz's conclusion is disputable. Strauss and Corbin (1991, 1994, 1998) were very clear about their departure from a positivist realist ontology and unambiguously expounded a post-positivist critical realist ontology. While they affirmed that there is an external, objective reality, they clearly identified that the analyst's grasp of it is limited, and "only God" can perfectly apprehend the "'real' nature of reality" (Strauss & Corbin, 1998, p. 4). Strauss and Corbin asserted that the purpose of social research is to journey towards an

"increasingly greater", but not immutable, representation of reality (Strauss & Corbin, 1998, p. 4). Strauss and Corbin located their altercation within the philosophy of symbolic interactionism and pragmatism, and emphasised their close affiliation with the philosophical writings of Dewey (1922) and Mead (1934) (see Appendix B). With this critical realist perspective, they argued that a "theory is not the formation of some discovered aspect of a pre-existing reality 'out there'" but instead emphasised that theories represent "interpretations made from given perspectives" (Strauss & Corbin, 1994, p. 279). They attested that the "human grasp of reality never can be that of God's" and as such all grounded theories are to some extent "fallible", "temporarily limited". and "provisional", particularly as they are forged within a particular culture and time and embedded in a specific historical context (Strauss & Corbin, 1998, p,4; 1994, p. 279, 280). Ultimately, Strauss and Corbin's assertions are consistent with a post-positivist paradigm which contends that "although reality exists to be uncovered by inquiry, it is never perfectly apprehensible" (Ghezeljeh & Emami, 2009, p.17; Guba & Lincoln 1994).

While countering the philosophical positions of Classic and Straussian GT, Charmaz clearly defined her differing ontological, epistemological and methodological position (2000, 2006). Charmaz described refashioning the methodology of GT by reclaiming the powerful tools of GT from their positivist origins to forge a more flexible, intuitive and open-ended methodology which dovetails with a constructivist paradigm (Charmaz, 2000). Her Constructivist GT is unambiguously underlined by a relativist ontology, which presupposes the existence of manifold social realities (Charmaz, 2000, p. 510). Charmaz emphasised that her epistemological position unequivocally endorses the researcher and participant's co-construction of knowledge and mutual interpretation of meaning, with the objective of fashioning an interpretive depiction of participant's experiences (Charmaz, 2000). Ultimately, Charmaz argued that her alternative Constructivist GT not only "offers accessible methods for

taking research into the 21st century" but also represents "a middle ground between postmodernism and positivism" (Charmaz, 2000, p. 510).

However, Charmaz's depiction of Constructivist GT as a middle ground between the polarities of postmodernism and positivism is questionable. Charmaz's Constructivist GT is closely associated with a postmodernist relativist ontology (encompassing many realities), a postmodern relativist epistemology (denoting a high influence of the researcher in the research), and a postmodern interpretative rendition of the GT methodology (salvaging it from its positivist roots). Consequently, rather than representing a middle ground between postmodernism and positivism, Charmaz's constructivist paradigm is closely correlated with a postmodernist philosophy. Perhaps the true middle ground between postmodernism and positivism is in fact post-positivism, as it encompasses the balance of a critical realist ontology and relativist epistemology.

Ultimately, each variation of GT corresponds with a distinct philosophical tradition. In Classic GT a theory is *discovered* within a positivist paradigm, in Straussian GT a theory is *created* within a post-positivist paradigm, and in Charmaz's GT a theory is *constructed* within a constructivist paradigm. The deliberation of choosing the most appropriate expression of GT will be delayed to consider each variation of GT in its entirety.

4.7 The Use of Literature

As a result of their contending philosophical frameworks, the Classic, Straussian and Constructivist GT stances on the use of literature is divergent. Glaser and Holton (2004) recommended that when embarking on research, the GT analyst should suspend any pre-existing knowledge from literature or professional/personal experience, to ensure an open

mind, free of undue influences. This position encapsulates the aspiration to remove any undue influences from the research. Furthermore, Glaser asserted that it is essential not to consult relevant academic literature prior to, or during the process of, undertaking a GT study. He argued that prior knowledge "violates the basic premise of GT" as it clouds and compromises the analyst's ability to perceive a dynamic new concept which has not featured in the aforementioned literature (Glaser & Holton, 2004, para. 46). Glaser advised that consulting the literature should be restricted to a *constant comparison* at the end of the study, at which point a specific literature review may be compiled if desired. Ultimately, Glaser's position was indicative of the positivist axiological "concern to not contaminate, be constrained by, inhibit, stifle or otherwise impede" the natural emergence of theory from data (Kelle, 2005, p. 31).

Strauss and Corbin challenged Glaser's position. They encouraged the appropriate use of literature at every stage of the study, discerning the difference between an *empty head* and an *open mind* (Strauss & Corbin, 1990; Kelle, 2005). They argued that the analyst's previous experience and exposure to the subject, as well as a wide variety of literature may (and should) be employed throughout all phases of the research, from conception to conclusion (Charmaz, 2006, Strauss & Corbin, 1990). This is consistent with their post-positivist axiology which accepts that the researcher inevitably influences the research. Strauss and Corbin (1990) maintained that a prior and on-going consultation with pertinent literature engenders manifold benefits: it reveals gaps in the academic literature; it can be employed as a secondary source of data; it can inspire questions; it can guide theoretical sampling; it can be utilised for supplementary validation; and it provides an insight into existing theories and philosophical frameworks. However, Strauss and Corbin's engagement with the literature was not unqualified. While they affirmed the use of literature at every stage of the research, they did not recommend an exhaustive and comprehensive prior review of *all* the relevant literature before embarking on research. They warned that "we do not want to be so steeped in the

literature as to be constrained and even stifled in terms of creative efforts by our knowledge of it" (Strauss & Corbin, 1990, p. 50). Thus, while embracing the continuous use of literature, Strauss and Corbin also advised restraint, to guard against becoming so blinded by it as to prevent a new revelation of the studied phenomena. This is consistent with the critical realist concern to strive for the closest representation of reality as possible.

Charmaz echoed Strauss and Corbin's endorsement of literature but developed it a step further. She suggested that the literature should be compiled in a specific literature review chapter as well as interspersed throughout the entire thesis (Charmaz, 2006, p. 166). To guard against this danger of becoming immersed in literature to the extent of losing one's creativity, Charmaz advised delaying writing a specific literature review chapter until after data analysis. She proposed that this resolution would facilitate a comprehensive literature review without compromising the researcher's openness and creativity. She argued that a comprehensive literature review, compiled after data analysis, is efficacious for a number of reasons: it facilitates the researcher to enter into the dialogue of the pertaining academic field; it reinforces the researcher's credibility, authority, and ensuing argument; and it can justify and explicate the researcher's rationale in the ensuing chapters of the thesis (Charmaz, 2006, p. 166-167). Furthermore, the balanced approach of utilising literature at every point of the research, but delaying total immersion until the end of the study, efficaciously augments, rather than asphyxiates, creativity. Charmaz's position is consistent with constructivist philosophy, which insists that research does not occur in a vacuum, but rather is influenced and informed by the context in which the researcher is operating.

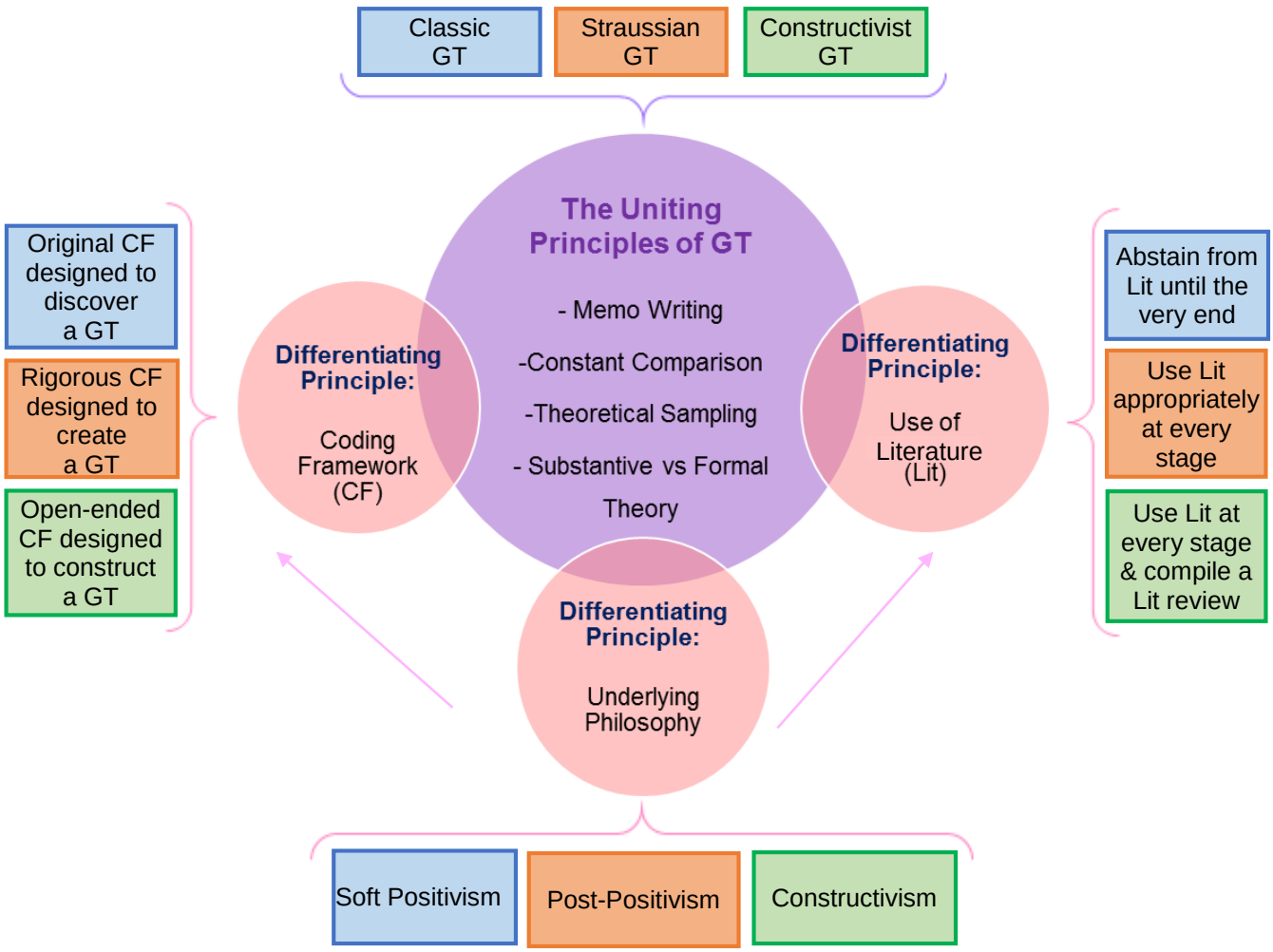
Strauss and Corbin also argued that consulting the relatable academic literature can effectively augment the researcher's theoretical sensitivity. They explained that theoretical sensitivity encapsulates "the ability to recognise what is important in data and to give it meaning" (Strauss and Corbin, 1990, p. 46). Glaser warned that consulting literature risks

jeopardising this ability as it may cultivate *a priori* assumptions, causing the researcher to filter data through predetermined ideas (Glaser and Holton, 2004). He argued that this could "force preconceived notions" on the data, and impair the researcher's sensitivity to carefully apprehend participants' self-disclosed concerns (Glaser and Holton, 2004, para. 44). However, Bryant disparaged Glaser's *tabula rasa* aspiration, contending that it is impossible for the researcher to approach the study devoid of any preconceptions (Bryant 2002; Urquhart, 2002). Strauss and Corbin also refuted Glaser's rationale. They contended that surveying the published literature (particularly material which is descriptive in nature with little interpretation) enhances theoretical sensitivity as it can attune the researcher to the field, inform what questions they ask, sensitise the researcher to recurring emic concerns and issues, and fine-tune their capacity to discern subtleties in the data they may otherwise miss (Strauss & Corbin, 1990). Consequently, in contrast to Glaser who warned that a literature review risks "thwarting" theoretical sensitivity, Strauss and Corbin argued that literature can stimulate and enhance theoretical sensitivity (Glaser & Holton, 2004, p. 46).

4.8 Choosing the appropriate GT

While composing this chapter the researcher has become increasingly convinced that it is essential to comprehend the principles that unite and differentiate the three traditions of GT, in order to clearly locate her research endeavour within a particular GT tradition, and defend the rational for selecting one variation above the other two. Accordingly, the final diagram (Figure 4.4) below provides a visual map to succinctly illustrate the points of convergence and divergence between Classic, Straussian, and Constructivist GT.

Figure 4.4 The Uniting and Differentiating Principles of GT



Legend for Figure 4.4

- The purple circle encompasses the uniting principles which are embraced by all three factions of GT.
- The three pink circles indicate the three areas of contention where the three traditions of GT disagree.
- The blue boxes signify Classical GT positions
- The orange boxes signify Straussian GT positions
- The green boxes signify Constructivist GT positions
- The pink arrows indicate the influence of one disputed precept on another.
- CF is an acronym for Coding Framework; Lit is an abbreviation for Literature.

As illustrated in the concluding diagram (Figure 4.4), the three traditions of GT are distinct entities. Constructivist GT embodies the most contemporary expression of the methodology. As well as adjusting GT to the contemporary methodological climate, Charmaz provided a comprehensive overview of the history of GT and depicted the previous two variations of GT with striking lucidity. She also provided succinct definitions of core GT tenets and exceptional insight into interviewing participants. However, Constructivist GT emanates a distinctly postmodern flavour of GT. The corresponding relativist ontological position and epistemology denoting a co-construction of data was rejected in the previous chapter. Furthermore its strong emphasis on descriptive capture and indefinite, relaxed coding procedures are not congruent with the overarching aim of this study to conceptualise rather than describe emic experiences of parents coping with UNHS. Thus, Constructivist GT is not the appropriate methodology to structure this study. Nevertheless, pertinent features of Charmaz's literature, particularly with regard to interviewing, will be consulted at various stages of the research.

Classic GT encapsulates the original formation of GT. Glaser's later publications, in particular, present this Classic GT as an innovative, accessible, and comprehensible methodology. However, specific precepts, such as refraining from a literature review prior to research, represent difficulties for the researcher as she ascertains that a review of the literature would fine tune her theoretical sensitivity and reveal gaps in the corresponding academic field. Furthermore, the positivist principle of trusting in the natural emergence of a theory from data to be *discovered*, is not acquiescent with the researcher's post-positivist ontology. Furthermore, the "internal misalignment" of Classic GT, due to the incongruence of a positivist paradigm and an interpretative coding procedure, represents an inherent difficulty with the classic methodology (Jones & Alony, 2011, p.4; Bryant, 2002). Additionally, in complete contrast to Constructivist GT, Classic GT eliminates virtually all descriptive capture with an emphasis

exclusively on abstraction. While the goal of this study is conceptualisation, the researcher believes that the emic experiences of participants are important to acknowledge and portray to some extent for the purpose of illustrating the context from which the theory emerges. Consequently, Classic GT will not be selected to undergird this study. Nonetheless, the helpful aspects of Glaser's literature will be referred to during the course of research.

Straussian GT represents the most complex formation of GT. The complexity of the coding procedure is often criticised as excessive, rigid, formulaic, overly-prescriptive, and detrimental to creativity. However, it can also be appreciated as rigorous, systematic, comprehensive, and thorough. Furthermore, the coding procedures were not designed to be rigidly adhered to with austere or inflexible stringency, but can be adapted to individual studies and relaxed appropriately (Strauss & Corbin 1990, 1998, 2008). Indeed Strauss and Corbin confirmed that "it would be unrealistic to assume or even suggest that researchers will use every procedure described in this book" and reiterated that the mechanisms were designed to be employed flexibly and creatively, with discretionary application (Strauss & Corbin, 1998). Additionally, Straussian GT has many other compelling features: it endorses the use of literature at every stage of research, it balances the incorporation of the participant's voice into research while maintaining the objective of conceptualisation, and it is underlined by a post-positivist paradigm which was selected in the previous chapter, as an appropriate paradigm to structure this study. Therefore, the researcher has identified Straussian GT, as the most appropriate, adept and proficient methodology to structure this study.

4.9 Conclusion

This chapter traced the process of ascertaining the most incisive strategy of inquiry to undergird this study. The assessment culminated with the selection of Straussian GT which

was congruent with both the researcher's academic aspirations and philosophical convictions. Consequently, prior to embarking on data collection the researcher had definitively designed her guiding philosophical and methodological framework. The following table summarises her design.

Table 4.4 The Revised Provisional Research Design of this Study

Overarching Paradigm	Ontology	Axiology	Epistemology	Methodology	Strategy of Inquiry
(Soft) Post-Positivism	Critical realism	Values influence the research	Subjectivism	Largely qualitative, inductive, emic, with the objective of explanatory understanding	Straussian Grounded Theory

The clause "provisional" is purposefully maintained in the title of this table. During the process of translating this design into practice, the researcher confronted practical considerations and challenges which necessitated the refinement of this design. The following chapter outlines this dilemmas of confronting and resolving emerging issues in the transition of theory to practice.

5. Executing Research: From Theory to Practice

5.1 Introduction

As detailed in the previous chapter, the researcher selected Straussian GT as the optimal strategy of inquiry to complete the research design of this study. The act of translating this theoretical methodology into practical reality necessitated a number of pragmatic decisions regarding instrumentation, recruitment, the timing of data collection, etc. During this process the researcher confronted unanticipated challenges which precipitated a refinement of her research design. This chapter details these decisions, developments, and dilemmas, along with their subsequent resolutions.

5.2 The Primary Instrument of Data Collection

The subject of this study determined the criteria for selecting an instrument of data collection. The investigation of the parental journey necessitated an instrument which was capable of an in-depth qualitative exploration of parents' emic experiences with a capacity to inductively draw out and theorise the nuances and complexities of their personal stories. While Straussian GT embraces manifold instruments of data collection (including field observations, public records, questionnaires, descriptive literature etc.), the tool of interviewing is consistently identified as particularly adept in its capacity to fulfil the criteria outlined above. Strauss and Corbin (1998) explained that interviewing is underlined by the aspiration to uncover the participants' concerns and understand what issues they defined (and experienced) as problematic or profound. This inductive approach to the prioritisation of the participants' emic concerns provides the focus not only for qualitative interviewing but also for the entire research project and diminishes the "risk" of the study becoming "irrelevant or merely trivial" (Strauss and Corbin, 1998, p. 38). The interviewer carefully observes how the participant

interprets phenomena, negotiates situations, and responds accordingly (Strauss & Corbin, 1998). Consequently, semi-structured interviewing was selected as the primary (but not sole) instrument to achieve the objective of this study.

While affirming the use of this instrument, Straussian GT had limited guidelines for its implementation. To resolve this shortcoming the researcher consulted Charmaz's guidelines on the subject. Charmaz (2006) advised that the interview questions need to be broad enough to elicit unanticipated responses, but also sufficiently narrow to provide a concentrated exploration of pertinent issues. She suggested that the questions also satisfy the ethics committee with enough specificity to assure evaluators that the research will cause no distress, while maintaining enough openness to unlock an array of unanticipated experiences and insights (Charmaz, 2006). To achieve this balance, Charmaz (2006) recommended fashioning a short list of carefully crafted questions to guide and direct the interview. She suggested that this can release the researcher to concentrate on the responses rather than on what the next question should be. Subsequently, the researcher selected and modified the following interview questions for parents from Charmaz's synopsis of suggested questions (2006, p.30-31):

- Can you tell me your experience of learning that your child has a hearing loss (from neonatal hearing screening until now)?
- Tell me your thoughts and feelings during the screening/diagnostic process. In what ways did that affect you? Your family?
- What problems did you encounter? How did you respond?
- Who/what has been the most helpful to you during this time? Why?
- As you look back on the screening and diagnostic process are there any other events that stand out in your mind? Can you describe this? What effect did this have? How did you respond?
- After having these experiences, what advice would you give to someone in the process of learning that their baby has a hearing loss? What advice would you give to the (medical) staff?
- Is there anything else you would like to add?

While refraining from offering practical guidelines, Strauss and Corbin nevertheless advise gathering a diverse breadth of data from a range of sources to elicit multiple perspectives

of the same event (1998). Consequently, while primarily focusing on interviewing parents, the researcher also invited select professionals to be interviewed at appropriate junctures. The purpose of this etic inclusion (which was supplementary to the prioritisation of the emic parental perspective) was to enhance the study with a multi-dimensional perspective and to address emerging gaps in the research (for example with regard to ambiguity in the early-intervention system, and to address specific questions regarding parental withdrawal and denial). The subsequent interview questions were appropriately adapted for professionals (Charmaz, 2006, p.30-31):

- What is your role with regard to neonatal hearing screening? Can you describe your experiences of this?
- What problems do you encounter? What problems do parents encounter? How do you/they respond?
- What do you think is most helpful to you/ to parents during this time? Why/how does this help?
- As you consider the screening and diagnostic process, are there any other key events that stand out? Could you describe them? What effect does this have? How do you respond?
- Is there anything you would change with the screening/diagnostic process?
- Is there anything else you would like to add?

In the process of data analysis the professionals' perspectives were supplementary and subservient to the data generated from parents. As the Findings Chapter was composed the vast majority of quotations were taken from parents rather than professionals. This ensured that the parental voice was paramount and that their experience guided the study.

5.3 Research Sample and Recruitment

In March 2013, having received ethical approval from the Clinical Research Ethics Committee (CREC) in Cork University Hospital (this process is detailed in section 5.9) the researcher commenced the recruitment process. This entailed collaborating with administrative and clinical professionals who were actively involved in the Universal Neonatal Hearing

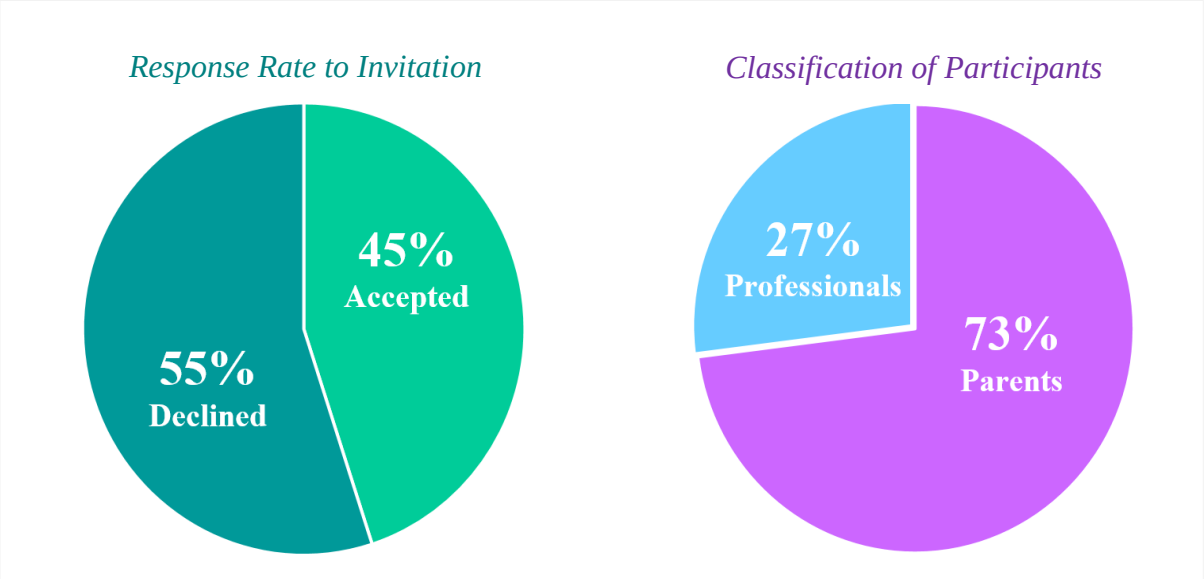
Screening (UNHS) programme in the Health Services Executive (HSE) in Ireland. The researcher was guided by the GT principle of theoretical sampling which stipulates that the entire research sample is not predetermined at the genesis of the study. Instead, the sampling encompasses an evolutionary process as the analysis of data reveals the need for more data (Strauss & Corbin, 1990, 1998). Thus, at the commencement of data collection, the researcher exclusively invited parents (whose child had received a diagnosis through the UNHS programme) to participate in the study.

Contact information was released to the researcher on the basis of parents' previous consent for their information to be utilised in order to document and improve the UNHS system in Ireland. Over the course of 6 months (May 2013 to October 2013) the addresses of 24 families was issued to the researcher by the HSE. The researcher invited all 24 families to participate in the study through a postal invitation consisting of a letter from the researcher, a letter from the HSE, and a detailed information sheet. In total, 10 families (more specifically, 11 individuals) responded affirmatively to this invitation, expressing interest in engaging in an interview. This represents a parental response rate of 42%.

As parents identified significant professional figures who impacted their journey (e.g. clinicians, visiting teachers of the deaf, social workers, charity workers, speech and language therapists, sign language tutors, etc.), the researcher proceeded to invite some of these professionals to interview. Furthermore, as the analysis of data revealed areas of ambiguity, the need for specific information guided the process of identifying and inviting targeted individuals to participate in this study. This demonstrations the application of the GT principle of theoretical sampling whereby the research sample was directed by the research process itself. Accordingly, over the course of data collection and analysis, the researcher invited a total of 7 professionals to participate in semi-structured interviews. Four of these professionals responded affirmatively which represented a response rate of 57%.

In summary, a total of 31 invitations were issued to individuals (24 to parents and 7 to professionals) to participate in semi-structured interviews. The researcher received a total of 14 affirmative responses (10 from families and 4 from professionals) which represents an overall response rate of 45%. While the professional input was invaluable and insightful, it was supplementary to the parental perspective which was prioritised throughout the process of data collection and analysis. This emphasis was reflected in decisions regarding the recruitment of respondents, 73% of whom were parents and 27% of whom were professionals. As evident in these statistics, parents were deliberately given the dominant voice within this research. The diagrams below depict these statistics.

Figure 5.1 Statistical Representation of Participation in Interviewing

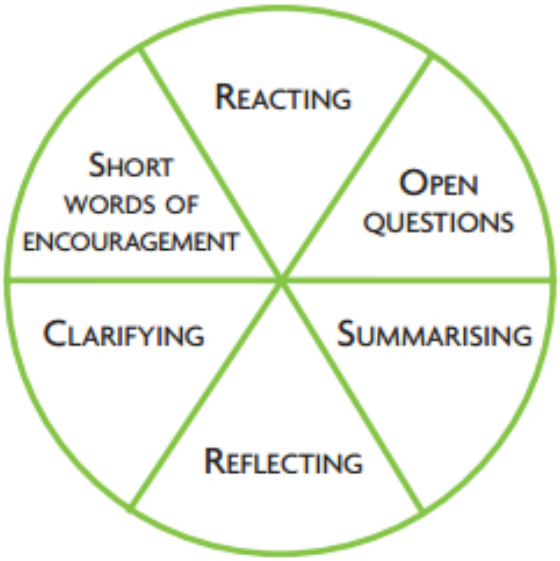


5.4 Conducting Interviews

In the act of undertaking semi-structured interviews, Charmaz proposed the principle of active, rather than passive, listening. She asserted that the "role" of the interviewer is to "help the research participant to articulate his or her intentions and meanings" (Charmaz, 2006, p. 26). Not only does the researcher empathetically listen and carefully observe, they also need to actively draw out the participant's perspective by encouraging and supporting their responses

(Charmaz, 2006). The *listening wheel* (designed by the Charity *Samaritans*) summarises the following six listening skills which are designed for this purpose (Moran et al, 2011).

Figure 5.2 The Samaritans' Listening Wheel



(Retrieved from Moran et al, 2011, p. 9)

1) **Open-Ended Questions**: Rather than implying an answer or eliciting a yes/no response, open-ended questions invite the participants to voice their perspective. These questions often begin with: *How? Where? What? Why?* (Moran et al, 2011).
2) **Short words of encouragement**: words such as *yes, um hmm, of course, tell me more* etc. encourage the participant to continue telling their story and conveys the researcher's active engagement and interest (Moran et al, 2011).
3) **Reflecting**: Echoing a significant phrase or word, by repeating it back to the participant (e.g. grieved for six months), displays a careful attention and affirmation, and supports them to further expand and reflect upon a specific issue (Moran et al, 2011).
4) **Clarifying**: If a particular detail is unclear the researcher can gently ask clarifying questions. As well as enhancing the researcher's comprehension, this also draws out the participant's reflections in greater depth and augments self-awareness (Moran et al, 2011).
5) **Reacting**: It is essential to respond empathetically to a deeply personal disclosure. Responses such as "that was a very stressful situation" communicates sympathetic understanding and is imperative to "building rapport and trust" (Moran et al, 2011, p.9).
6) **Summarising**: Carefully summarising the participant's experience communicates an acknowledgment of their experience and is also a useful technique to draw the interview to a close (Moran et al, 2011).

The researcher actively utilised these six listening skills while conducting semi-structured interviews with participants. These six techniques enhanced her capacity to actively listen and facilitated the process of drawing out the participants' perspective. These six listening skills also informed the researcher's compassionate engagement when encountering participant vulnerability.

Although this research encompassed relatively few risks, the subject of parent vulnerability necessitated particular concern and care. Within the ethics form (see section 5.9), the researcher identified that recounting memories of their child's hearing loss during an interview, may be an emotional topic for some participants to discuss. In order to care for parents in this predicament the researcher implemented precautionary measures, each of which were detailed in her application for ethical approval. Firstly, during the recruitment stage the researcher clearly highlighted all risks in the literature provided to parents. She emphasised that while infant hearing loss may be an emotional subject to discuss, all participants are fully entitled to skip any question, take a break, or terminate the interview at any stage, without any negative repercussions. Secondly, this reassurance was reiterated to parents prior to the commencement of each interview. Thirdly, while conducting an interview, if a participant was upset the researcher responded empathetically, and at the appropriate moment (without interrupting them) offered the parent the opportunity to take a break and attended to their needs (offered tissues, asked if they wanted a cup of tea, ensured they wanted to continue etc.). Fourthly, in this predicament, the researcher also requested the parents' permission to contact them later that day to inquire if they had recovered.

When a small minority of parents were upset during the interview, the above procedures were followed as appropriate. However, far from representing a negative experience, the process of relaying their story appeared to be an opportunity to unburden themselves and for

their voice to be heard. For one parent in particular the outpouring of grief seemed to bring relief, and the interview, although emotionally laden, was therapeutic rather than distressing. Importantly, as the researcher offered to pause the interview this parent was in a position to indicate herself if she wished to take a break or continue. On completion of the interview, the researcher offered follow-up contact with this parent to ensure her emotional wellbeing, but the parent declined. This parent was already connected to a system of services with ongoing professional contact.

The researcher had a procedure in place for responding to acute vulnerability. If the researcher had an overwhelming concern for a participant, for whom the interview was causing distress, she had a protocol of taking the initiative to terminate the interview immediately. She outlined in her ethics form that in this circumstance she would then proceed to arrange follow-on support, for example ensuring the parent have transport home, offering to contact anyone whom they would like to support them, recommending they seek further support (from their family GP, counsellor, visiting teacher of the deaf etc.). In the case of an enduring concern the researcher had arranged to inform her supervisor and the Clinical Research Ethics Committee of her assessment, requesting further intervention for the parent.

However, while it was helpful to have this protocol in place, this level of action was unnecessary. Each parent in the sample was already linked into a multi-disciplinary team of supports and services. All the participants in this sample were in a position to indicate themselves if they wished a break. Furthermore, the majority of parents presented as positive and hopeful. Nevertheless, regardless of emotional response, the researcher debriefed with participants after each interview, asking how they were on completion of the interview and inquiring if they had any further questions regarding the study.

5.5 Transcribing Interviews

Strauss and Corbin advised recording interviews and recommended that the initial recordings should be entirely transcribed word-for-word to ensure analysis is thorough and that important data is not lost (1990). They suggested that as the study matures, and categories and concepts solidify, it is only necessary to transcribe the relevant sections of evidence which relate to the emerging hypothesis (1990). These guidelines were adhered to as the researcher transcribed her first eleven interviews verbatim without filtering out extraneous material. When analysing her final three interviews, she transcribed only the relevant sections as her emerging conceptualisation was reaching the point of saturation.

The art of transcription encompasses subtle complexities. The translation of an interview from one medium to another inevitably necessitates a certain amount of selection, discretion, and judgement on the part of the researcher who inevitably exercises their interpretive influence in this process (Lapadat & Lindsay, 1998). While acknowledging their inevitable impact, the post-positivist researcher is also compelled to depict as close a representation of reality as possible, and capture nuances of verbal and non-verbal information. With these considerations in mind a number of transcription conventions have arisen which provide a lexicon of symbols designed to represent the subtleties of interpersonal communication as accurately as possible. These symbols allow the researcher to represent nuances of speech and interaction and thus provide a richer depiction of interaction. However, Strauss and Corbin's (1990) directions regarding the act of transcription do not explore this important issue.

In the absence of guidance from Strauss and Corbin on this subject the researcher consulted the transcription convention fashioned by Gail Jefferson which is the "internationally recognised "gold standard" for transcribing" (Lerner, 2004, p.3). Jefferson's convention provides a systematic glossary of symbols which allow the analyst to represent the richness and

subtlety of human interaction with particular precision. After a careful analysis of the Jefferson (2004) transcription convention the author selected the following symbols to enhance her transcriptions of collected data:

Table 5.1 Selected Symbols from Jefferson's Transcription Convention

Symbol	Jefferson's Explanation of Each Symbol (2004)
<u>Word</u>	*Underscoring* indicates some form of stress, via pitch and/or amplitude (Jefferson, 2004, p. 25)
WORD	*Upper case* indicates especially loud sounds relative to the surrounding talk (Jefferson, 2004, p. 27)
°**word**°	*Degree signs* bracketing an utterance or utterance-part indicates that the sounds are softer than the surrounding talk (Jefferson, 2004, p. 27)
( )	*Empty parentheses* indicate that the transcriber was unable to get what was said (Jefferson, 2004, p. 31)
(word)	*Parenthesized* words and speaker designations are especially dubious (Jefferson, 2004, p. 31)
(blerf)	*Nonsense syllables* are sometimes provided, to give at least an indication of various features of the un-gotten material (Jefferson, 2004, p. 31)
((crying))	*Doubled parentheses* contain transcriber's descriptions (Jefferson, 2004, p. 31)

The author deliberately restricted her employment of the Jefferson transcription convention to the above selected symbols. She specifically chose not to exhaustively employ every symbol in the Jefferson's glossary as an indiscriminate use would have rendered a finished transcript akin to the following:

> Jessie:→ [·h An' that whether he thow:t thet I ed'n ac[cidn't] [ohr someth]ing...
> Ada: → [I : : : :]:[k n e o : w] (Jefferson, 2004, p.18)

This level of nonverbal information which mirrors accents, duration of pauses, and documents interruptions is unnecessary for this study as it is not concerned with a fastidious conversation analysis. In addition, an exhaustive representation of non-verbal information would render

quoted sections of interviews (included in this study or related publications) virtually unreadable to anyone unfamiliar with the glossary. Furthermore, as the content of these transcripts will be fragmented in open coding, rather than analysed as a discourse analysis, many of the symbols, would lose their context and become meaningless. Thus, the researcher adapted the Jefferson transcription convention by applying it selectively, sparingly, and in a simplified manner to suit the needs of this particular study.

As the researcher became more adept at transcribing interviews she recognised the need for additional symbols to either enhance, clarity, or safeguard confidentiality. In response to this identification she incorporated the following symbols into her study.

Table 5.2 Additional Symbols

Symbol	Explanation
[the]	A word in *squared brackets* indicates a word the author has inserted for clarity
…	*Three full stops* in a row indicate either the omission of an irrelevant section, or the omission of identifiable information which would risk compromising confidentiality. This was largely employed in the incorporation of a quote into this study
. **—** **((pause))**	*One full stop* indicates a short pause, an *underscore* symbol represents a longer pause, and the word ((pause)) in *double parenthesis* illustrates a particularly long pause

The totality of these symbols were indispensable not only in the transcription of audio recordings but also in the process of incorporating quoted extracts from interviews into the body of this study.

5.6 Interview Schedule

As outlined in the previous chapter, Straussian GT stipulates a distinctive approach to the collection, transcription, and analysis of data. Rather than representing distinct phases of

the research, the three undertakings should occur simultaneously within a GT study as the analysis of data should highlight emerging gaps in the study and subsequently guide and refine the further data collection. In keeping with these principles, the researcher undertook her interviews in four distinct rounds over the course of 17 months. The table below illustrates this schedule.

Table 5.3 Four Rounds of Semi-Structured Interviews

Round	Date	Number of People Interviewed	Number of Interviews
Round 1	May/ June 2013	4	3
Round 2	September 2013	4	4
Round 3	October 2013	4	4
Round 4	September 2014	3	3

This schedule was primarily ordered to embody the GT principle of interspersing data collection with transcription and analysis. However, it was also influenced by external factors such as the approval of the ethics committee, the researcher's access to participant contact information, the practical feasibility of conducting interviews, the availability of participants, the geographical location of the researcher, and the timeframe of the study. Far from deterring the adherence to GT principles, these practical considerations created a context in which to apply and adapt them.

While maintaining as much distinction as possible between the rounds of data collection[16] the researcher carefully coded and analysed each round separately. This process is clearly illustrated in the Appendix E of this study with photographs of each stage of data

[16] Due to the practical circumstances of the researcher, the data collection for Round 2 and Round 3 occurred in quick succession. However, the researcher maintained the demarcation between these two rounds by ensuring they were analysed separately and distinctly. This is clearly illustrated in Appendix E.

analysis which are colour-coded to illustrate the four distinct rounds of coding. Significantly, by the time the researcher was analysing Round #3 of interviews, she began reaching the point of saturation whereby the codes, categories, and resultant conceptual framework were dense and comprehensive and confirmed through successive data collection and analysis. In the final round of interviewing she discovered some anomaly cases such as the unique dynamics of a dual-diagnosis, potential medical complications, or a previous family history of hearing loss. However, the conceptual framework she had previously fashioned through data analysis had the flexibility to account for these differences.

5.7 Encountering Difficulties in Coding and Software

The process of coding interviews precipitated unanticipated challenges and represented one of the greatest struggles of this study. During the first round of data the researcher embarked upon coding interviews equipped with the fastidious instructions of Straussian GT, which she initially employed in a strict and concentrated capacity. However, as her codes and categories became more dense and complex, and she began to forge her conceptual framework, it soon became evident that the parameters of Straussian GT were too restrictive, particularly its use of symbolic interactionism as a hermeneutic for ordering data. With ongoing analysis it became increasing evident that her data did not fit into the cause-action-consequence framework of Straussian GT, nor did it acquiesce with the proposed paradigm model. The more the researcher attempted to remain faithful to the Straussian formulaic framework, the more evident it became that she was effectively manipulating the data into a mould which did not naturally fit the key themes of her study. Significantly, this conflict was augmented with each successive round of coding.

Eventually, after months of struggling with these tensions, the researcher accepted the inevitable and relaxed her coding strategy to the extent that it resembled the Classic GT approach to coding. This solution resolved the tensions she had been struggling with, and allowed her to tease out the core categories of her data in a more dynamic capacity. It is critical to highlight that this resolve did not violate the parameters of Straussian GT as Strauss and Corbin strongly reiterated that the researcher should employ their coding framework with flexibility and discretion, adapting their use of the tools to suit their specific study (Strauss & Corbin, 1990). Thus, while remaining within the post-positivist philosophical framework of Straussian GT, the researcher has incorporated specific methodological directives from both Constructivist and Classic GT into her research design.

As well as working through difficulties with the coding framework, the researcher also encountered difficulties with the qualitative data analysis software NVivo. Initially, when embarking on Round #1 of data analysis, she considered it to be an invaluable resource, allowing her to code vast quantities of data, and condensing codes into manageable categories that could be altered with the intuitive features of the software. However, as the coding became increasingly dense and complex, she soon found the software to be more limiting than helpful. As a visual thinker, the researcher found it more helpful to illustrate the categories and sub-categories horizontally, in a colour-coded manner, with the freedom to draw arrows, move around sub-categories, and refashion the groupings accordingly. NVivo had a very limited capacity for such a visual ordering of data, which the researcher increasingly found to be more obstructive than helpful. She eventually discovered it was far more beneficial to manually draw out the codes, physically attach them to a wall, and work through the categorisation tangibly. She employed Microsoft Word in this endeavour, typing up and printing out the categories in a systematic capacity, and carefully positioning them on her office wall (see photographs of this process in Appendix E). She printed the coding arising from each round of interviews on

different colour paper (Round #1 in white; Round #2 in yellow; Round #3 in red; Round #4 in blue) to distinguish between different layers of coding. Ultimately, this approach was slower, but more effective for her visual categorisation of data.

5.8 Principles of Trustworthiness

In qualitative research the term trustworthiness refers to the quality of the research produced. Lincoln & Guba (1985, 2000) argue that the four pillars of *credibility, transferability, dependability,* and *confirmability* represent the determining criteria for evaluating the trustworthiness of a research endeavour. These criteria are consistent with the post-positivist position adopted in this current study. Each of these four principles are important to define and consider in order to defend the trustworthiness of this present study.

The first principle, *credibility,* encompasses the question of "truth value" (Lincoln & Guba, 1985). It essentially addresses the extent to which the researcher can claim her research findings authentically characterise the studied phenomena (taking into account the researcher's influence, interpretation, and perception of reality) (Lincoln & Guba, 1985). Lincoln & Guba suggest a number of techniques to enhance credibility, five of which were particularly germane to the present study.

The technique of "prolonged engagement" represented the "investment of sufficient time to achieve certain purposes: learning the 'culture', testing for misinformation…, and building trust" (Lincoln & Guba, 1985). Within the present study, the researcher spent from May 2013 to April 2015 engaging in in-depth interviews with participants (see section 5.6 for interview schedule), coding and classifying the collected data, writing up and refining the findings, and critically engaging with related publications (see appendix E). Within this "prolonged

engagement" the researcher built trust with participants in individual interviews, was attuned to potential misinformation (the researcher upheld the parental voice as paramount in the case of any discord between the parent and professional perspective), and carefully studied the nuances and subtleties of parental experience. This "prolonged engagement" also encompassed the further technique of "persistent observation" which encompasses depth of analysis (Lincoln & Guba, 1985). Within the present study the procedure of GT analysis enabled the researcher to "identify those characteristics and elements…that are most relevant to the…issue being pursued and [focus] on them in detail" (Lincoln & Guba, 1985). Furthermore, the researcher's meticulous documentation of this analytic process (see Appendix E) represents her fulfilment of the criteria to "describe in detail just how this process of…detailed exploration was carried out" (Lincoln & Guba, 1985, p.304). In addition, the researcher also engaged in the two further techniques of "member checking" and "triangulation" (Lincoln & Guba, 1985, p.304). The process of designing and undertaking this member check (which the researcher named a participant check) is detailed in section 5.9 of this chapter. Significantly, this participant check also corroborated the credibility of the present study with triangulation. The methodological concept of triangulation consists of analysing a single subject with multiple tools to substantiate a hypothesis (Berg, 2001, p.5). Having fashioned a conceptual framework through qualitative interviewing, the researcher proceeded to triangulate this finding with descriptive statistics gleaned though the participant check which consisted of a quantitative questionnaire to generate descriptive statistics. In addition, the final round of data collection presented the researcher with another technique of credibility, namely the "negative case analysis" (Lincoln & Guba, 1985, p.309). Having fashioned her conceptual framework at this point, the researcher undertook her final three interviews, each of which presented anomaly issues (i.e. multiple births, multiple diagnoses, and previous family history) which inevitably influenced the parents' journeys through the four stages. While these

anomalies prompted the researcher to refine her concepts, they also corroborated the credibility of her conceptual framework with the capacity to account for these differences. Thus, through her "prolonged engagement", "persistent observation", "member check", "triangulation", and "negative case analysis" the researcher can sufficiently claim the credibility of her study (Lincoln & Guba, 1985).

The second principle, *transferability*, represents the potential (but not necessarily the act) of applying the findings of the research to other contexts (Lincoln & Guba, 1985). However, Lincoln and Guba clarify the boundaries of the researcher's responsibility in this endeavour. They assert that it is not the researcher's task "to provide an *index* of transferability; it is his or her responsibility to provide the *data* base that makes transferability judgements possible on the part of potential appliers" (Lincoln & Guba, 1985, p.316). The researcher is therefore only "responsible for providing the widest possible range of information of inclusion" (Lincoln & Guba, 1985, p.316). This criteria is fulfilled in the findings' chapter of the present study. This chapter provides an in-depth, multi-faceted exploration of parental coping, taking into account context, diversity of experiences, anomaly cases, and the complexity of the subject. In addition, raw data also features prominently in this chapter, allowing the voice of the participants to pervade the analysis. While it is not the prerogative of this researcher to transfer these findings to other contexts (particularly as this is a substantive study), the potential to do so is nevertheless discussed in chapter 8 (see p.268).

The third principle, *dependability*, is intrinsically linked with the previous principle of *credibility*. Dependability encompasses the "classic notion of replication" to establish that the researcher's conclusions are indeed legitimate (Lincoln & Guba, 1985, p.317). Lincoln & Guba concede that the principle of replication presents a conundrum to the qualitative (or naturalistic) researcher who is engaged in a more "emergent" and organic research design whereby a "stepwise replication is a dubious procedure" (Lincoln & Guba, 1985, p.317). However, within

this study, the literature review provided a means of establishing dependability. As discussed at length in section 7.7 of the Discussion Chapter, a comparable study of parental coping with infant hearing loss was also undertaken by Hardonk et al (2011a) which encompasses an analogous framework of the parental trajectory. The similarity of both models is remarkable given they were both created in isolation from one another, within the different social and cultural contexts of Belgium and Ireland, within different healthcare systems, and with different sampling and research tools. This article was discovered after the researcher had fashioned her conceptual framework. While there are important differences and the researcher's model remains unique (as explored comprehensively in the Discussion Chapter) the Hardonk et al model nevertheless confirms the dependability of the researcher's conceptual framework.

The final principle, *confirmability*, encompasses the endeavour to prove that the research is "neutral" (Lincoln & Guba, 1985, p.300). This represents an alternative to the pursuit of objectivity, which is a problematic claim within qualitative research (as discussed in the Philosophical Foundations Chapter). However, the alternative (but comparable) principle of *confirmability* represents a concern to demonstrate that the research findings are not unduly influenced by the researcher's preferences and personality. The GT process of "memoing" was instrumental in this regard as it enabled the researcher to capture her evolving concepts as she undertook data analysis. It also provided a forum for her to reflect on and refine her concepts and, in the process, recognise and address her preconceptions, biases, and misrepresentations. An example of this is described in the Epilogue Chapter. Furthermore, the meticulous process of GT data analysis, documented in Appendix E, provided specific directions for analysis which safeguarded against the researcher manipulating the data to reflect her interests rather than the participants' concerns. In addition, the process of discussing the data analysis and findings with her supervisor was also extremely helpful for this refinement process. This was

crucial not only in establishing confirmability but also in the process of corroborating the credibility, transferability, dependability, and, ultimately, the trustworthiness of this present study.

5.9 Participant Check

In the later stages of the study, having completed the four rounds of data collection and analysis, the imperative to undertake a member check (which she named a *participant check)* to ascertain the trustworthiness of the resultant conceptual framework became increasingly evident to the researcher. This conviction was corroborated from three different vantage points. Firstly, from the participants' perspective, parents in the sample consistently expressed sincere interest in seeing the findings of this study and asked to be contacted again if they could be of any further help in this research. This sentiment was repeated during each round of data collection. The prospect of presenting findings to parents and requesting their feedback was therefore a means of acknowledging their contribution as well as valuing their assessment of the findings. Secondly, from a methodological perspective, GT recommends presenting findings to participants at the latter stage of the research for the purpose of participant evaluation. This endeavour bolsters the claims of a study and corroborates the credibility of the researcher's conclusions. Thirdly, in the Literature Review Chapter, the researcher highlighted and criticised the absence of studies which afforded respondents the opportunity to authenticate or refute the conclusions of the research in which they participated. The researcher criticised that this oversight prevents the voice of the parent from permeating every stage of the research process. Consequently, from these three distinct vantage points, the researcher was compelled to undertake a participant check.

Initially, the researcher planned to undertake this participant check by means of a focus group. This would have entailed inviting all the parents (who previously participated in interviews) to a presentation of the findings, with a follow up questionnaire to request their responses. However, given the geographical diversity and remoteness of the parents in this sample, inviting them to a single, or even multiple venues, was neither feasible nor practical, particularly as every family in this sample had young children. As a consequence, after much deliberation, the researcher and supervisor decided that undertaking the participant check by post would incur the least cost and demand on the parents in terms of time, travel, and finances. It would also enable a greater proportion of parents to participate. Therefore, it was identified as a more convenient and considerate means of affording parents the opportunity to engage in the participant check.

A subsequent proposal, outlining the details of this participant check was submitted to the Clinical Research Ethics Committee in December 2014. Upon receiving ethical approval in January 2015 (see Appendix D) the researcher proceeded to create a 15 minute DVD presentation of her research findings (available in Appendix D). She rang each of the parents who participated in interviews (one individual however was unreachable), and having received their unanimous permission by phone posted out the participant check pack to the 9 consenting families (consisting of 18 parents in total). This pack consisted of the DVD of research findings, an accompanying cover letter (incorporating an information sheet), two consent forms, two questionnaires, as well as a stamped addressed envelope.

Parents were invited to watch the DVD presentation of the findings, complete the questionnaire, and post it back to the researcher along with their signed consent form. The questionnaire (composed of 15 statements for participants to rate on a Likert scale) offered parents the opportunity to evaluate the conclusions of the study and their honest response was encouraged. The descriptive statistics generated from this feedback allowed the researcher to

substantiate the trustworthiness of her conceptual framework. This satisfied the three-fold endeavour of fulfilling the methodological prerequisite of validation, placing a high value on the parents' evaluation of findings, and addressing an important gap identified in the literature. In response to the participant check, the researcher received a total of 7 completed questionnaires from 5 families. These findings were analysed anonymously, computed to generate descriptive statistics, and incorporated into the body of the Findings Chapter.

5.10 Ethical Considerations

The entire process of translating this research design in to the pragmatics of data collection and analysis was undergirded by ethical considerations. The researcher engaged in a detailed analysis of two cornerstone documents, to ensure the utmost ethical veracity of this study. Firstly she consulted the Declaration of Helsinki which was composed by the World Medical Association (WMA) General Assembly in June 1965. Fashioned in the aftermath of the Nuremberg Trials (which exposed the inhumane experimentation conducted in Nazi concentration camps during World War II), the Declaration espoused a strong protective ethos and confirmed the status of research as subordinate to the wellbeing of the participant (World Medical Association, 2008; Carlson et al, 2004; Williams, 2008). This document is renowned as "the most widely recognised source of ethical guidance for biomedical research" (Carlson et al, 2004, p. 695). Secondly, the researcher consulted the *Code of Ethics* written by the National Association of Social Workers (NASW) Delegate Assembly[17]. Given the professional background of the researcher (as a Social Worker), as well as the social and psychological

[17] The National Association of Social Workers (NASW) represents one of the largest organisations of professional social workers to date and is based in Washington USA (2012). Their Code of Ethic's was selected above those of the International Association of Social Workers, or the Irish Association of Social Workers, because of its specific section pertaining to social work research which the other two did not include at the time of writing this chapter. This careful attention to research ethics was particularly important with regard to this current study.

concern of this study, it was crucial to consult a document specifically concerned with the ethical execution of social research.

These two documents reflect the multi-disciplinary nature of this study. The Declaration of Helsinki is primarily concerned with the impact of clinical research on human subjects, while the *Code of Ethics* concentrates on how to conduct social research ethically. This study is applicable to both these disciplines as it centres on an explicitly social concern (parental coping) within a clearly clinical context (diagnosis of infant hearing loss). Despite arising from different disciplines, both the WMA Declaration of Helsinki and NASW Code of Ethics strongly reiterated the following principles which were particularly apposite to this study.

- **Principle of Approval, Accountability, and Authority:** The proposed research protocol must be submitted to the appropriate and authoritative Ethics Committee for evaluation, approval, and accountability (WMA, 2008; NASW 2008).
- **Principle of Informed Consent, Voluntary Participation and Right to Withdraw:** Potential participants must be fully informed about the "nature, extent, and duration" of their requested engagement and made aware of their entitlement to withdraw from the research without any negative repercussions (NASW, 2008, ref. 5.02e). Informed consent must be obtained in a written format to formalise the enactment of this principle.
- **Principle of Wellbeing and Respect**: The researcher is ethically bound to safeguard the wellbeing of human subjects from "from unwarranted physical or mental distress, harm, danger, or deprivation" (NASW, 2008, ref. 5.02, j-i). If a concern for a participant's wellbeing arises, the researcher must also ensure the availability of appropriate follow up support. This duty of care supersedes all other considerations.
- **Principle of Disclosing Risks and Benefits**: The execution of research "must be preceded by careful assessment of predictable risks" as well as "foreseeable benefits" to

both the individual and any **"**communities affected by the condition under investigation". (WMA, 2008, para 18). There should be an open disclosure of these risks and benefits to all prospective participants (NASW, 2008).

- **Principle of Confidentiality and Privacy:** The researcher has an ethical obligation to protect the identity of participants and to safeguard "the confidentiality of their personal information" (WMA, 2008, para 23). This is essential to minimise any potential harm to participants.

The integration each of these principles into the composition of this study was crystallised during the process of applying for ethical approval. The researcher submitted two separate applications to the Clinical Research Ethics Committee (CREC) of the Cork Teaching Hospital. This endeavour fulfilled the principle of seeking ethical approval from an authority to whom the researcher is accountable. The first application to the Clinical Research Ethics Committee encompassed a *Protocol Submission Form*. This application was submitted to request approval to undertake semi-structured interviews with parents and professionals. It detailed the purpose and procedures of the proposed interviewing in meticulous detail, along with all accompanying documentation which would be posted to parents (cover letter, information sheet, consent form, and interview questions). It also highlighted and addressed important issues and principles such as informed consent, voluntary participation, confidentiality, maintaining transcripts of data, and the emotional vulnerability of participants. The researcher outlined detailed proposals to safeguard against any potential harm to participants. Her proposed safeguards were carefully in accord with the principles outlined in the Declaration of Helsinki and the NASW Code of Ethics. This application was successful and on the 28th March 2013, she received ethical approval to proceed with her research (see Appendix C).

In the final academic year of her study, December 2014, the researcher submitted a second application to the Clinical Research Ethics Committee entitled an *Amendment Submission Form*. This amendment outlined the unexpected development of deciding to undertake a participant check for the purpose of ascertaining the trustworthiness of the research findings. As well as encompassing a detailed description of the proposed procedures, protocols, recruitment process, and safeguards against harm the researcher submitted all supplementary documentation to the Ethics Committee (letter of invitation, information sheet, consent form, script of DVD presentation, and questionnaire). Like the previous application, her proposal was acquiescent with the principles outlined in the Declaration of Helsinki and the NASW Code of Ethics. This application was approved on the 6th January 2015 (see Appendix D), confirming the ethical veracity of this proposed execution of research. Significantly, in the practical application of these ethical standards, the necessity to be particularly cognisant of participant vulnerability and confidentiality was essential. Each of these issues will be discussed in turn.

5.11 Safeguarding Anonymity in Referencing

While all the ethical considerations were imperative, the researcher became increasingly concerned that the unique context of this study could potentially undermine the anonymity of participants. As UNHS was a recent innovation in an Irish context there was a limited amount of families and professionals working within the system. The risk of identification was therefore a pressing concern and it was essential for the researcher to take every precaution in safeguarding anonymity. To ensure the utmost protection of privacy, the specific disciplines of the professionals who participated in this research could not be disclosed. Within many disciplines associated with UNHS there are a limited number of specialised professionals whose identity may be evidenced simply by relaying their expertise. It was also imperative to

refrain from naming the specific geographical locations of participant recruitment and data collection as this identification risked a compromise of anonymity. In addition, every interview was transcribed with a pseudonym (e.g. P #1 for participant #1) to conceal the interviewee's name. As the study progressed the researcher increasingly omitted identifying information (geographical locations, name of child, etc.) from transcripts. Although the researcher alone was privy to the transcripts, she became increasingly cognisant of safeguarding the utmost confidentiality from the outset of data analysis. However, while this precaution was sufficient for transcription, extra care was essential in composing the Findings Chapter.

Even with all the above protections it became increasingly clear that while relaying quotations the removal of names and identifiable information was not enough to ensure anonymity. There was a potent danger that with accumulation of quotations throughout the chapter, the reader may be able to trace the culminated experience of a particular participant (e.g. Participant #1) and subsequently discover their identity. In order to remove this threat, it was essential to refrain from identifying each speaker and interview individually when including quotations in this study and instead compile all the transcripts into one document which was entitled *Interview Transcripts Compiled* (with the acronym *ITC*). This enabled the researcher to relay the voices of participants while safeguarding their anonymity.

In citing quoted extracts from interviews, the researcher sought to balance anonymity with the academic integrity of indicating the exact location of the quotation. To achieve this objective she created a referencing system whereby she specified the source of the quotation (*ITC*), followed by the page number (p.23), and followed by a semi-colon and the exact line number (: 32-36). A completed reference therefore resembled the following: (*ITC*, p.23: 32-36). Likewise, a similar referencing system was employed in the analysis of the completed participant check forms. She compiled parents' ratings of the 15 questions on a spreadsheet document to generate descriptive statistics. These resultant statistics were numbered according

to the question they related to (q.1, q.2, etc.) and referenced under the acronym *PCS* (*Participant Check Spreadsheet*). A reference was depicted as: (*PCS*, q.4). Any quotations from the comment section of a form was included at the end of the spreadsheet document and assigned a number. These quotations were labelled under the acronym C (for comment) and referenced numerically (eg *PCS*, c.1). No participants name appeared anywhere on the spreadsheet. Thus, this referencing template protected participant anonymity while ensuring academic transparency.

5.12 Memo Writing

The GT principle of memo writing was immensely significant in the composition of this research. Throughout the process of data analysis the researcher documented her personal and academic responses to the material through memo writing. This became integral in the process of forging and documenting theoretical developments. It provided a forum to capture immediate responses to data. It also provided a canvas for the researcher to paint the progression of an idea or concept as it matured throughout the process of data collection and analysis, proving a forum for the researcher to articulate the journey of wrestling with concepts and practicalities of research. Successive memos on the same subject effectively captured the conception and maturation of a concept throughout the research process. This was invaluable in refining the concepts of this study and during the process of composing the Findings Chapter.

5.13 Limitations

The greatest limitation of this study was the issue of time and scale. Given the inductive, emic, qualitative focus of this study the researcher concentrated on gathering in-depth data which encompassed detailed interviewing with extensive GT analysis. This concentrated focus was both a strength (as it fulfilled the objective of this research) but also a limitation (as it was

not practically feasible to engage with a broader sample of participants). This is a recurring characteristic of qualitative research, which prioritises *depth* over *breadth* of data. However, rather than compromising this study, the limitation of scale represents an opportunity for further research, and affirms the potential to develop the research findings beyond the confines of this study.

The response to the participant check represents a further limitation. The researcher posted 18 questionnaires (to 9 families) and received 7 completed questionnaires in response (from 5 families). This represents a response rate of 39%. The 7 responses the researcher received were generally affirmative (rather than critical) in their assessment of her research findings. While this positive feedback may be a testimony to the methodology of GT (which is designed to maintain a close connection with the collected data), it could also indicate that parents with a more critical response did not return the questionnaire. However, this possibility is speculative rather than definitive, as the low response rate may also simply be indicative of the lack of time parents have as they care for young children. Regardless of the reason, this limitation could also represent an opportunity to engage in further research following the completion of this study, to both corroborate and apply the findings. Specific recommendations in this regard are detailed in the Conclusion Chapter of this study.

5.14 Conclusion

This chapter opened with the researcher's resolute determination to employ Straussian GT as the guiding methodology of this study. However, the methodological barriers the researcher encountered necessitated an incorporation of aspects of Constructivist and Classic GT into her research design. This dynamic engagement with all three forms of GT does not violate the integrity of Straussian GT. Strauss and Corbin (1990, 1998) repeatedly insisted that the guidelines of Straussian GT should be employed in a flexible capacity and adapted to best

suit the unique dynamics of a study. The GT researcher does not necessarily have to adopt a pure form of one tradition and, indeed, within the parameters of consistency, there is freedom to blur the boundaries between Classic, Straussian, or Constructivist GT. Thus, while the researcher needs to ensure a consistent approach, there is nevertheless room for creativity and flexibility within the execution of the selected GT methodology. To acknowledge this creative adaptation, the researcher has re-classified her strategy of inquiry as an open-ended use of Straussian GT (with Classic and Constructivist influences). The table below encapsulates the final research design of this study, complete with all the unanticipated developments and resolutions.

Table 5.4 The Final Research Design of this Study

Overarching Paradigm	Ontology	Axiology	Epistemology	Methodology	Strategy of Inquiry
(Soft) Post-Positivism	Critical realism	Values influence the research	Subjectivism	Qualitative, inductive and emic, interviewing with the objective of explanatory understanding (supplemented with etic interviewing and triangulated with a quantitative questionnaire)	Open-Ended Straussian Grounded Theory (with Classic and Constructivist influences)

6. Findings

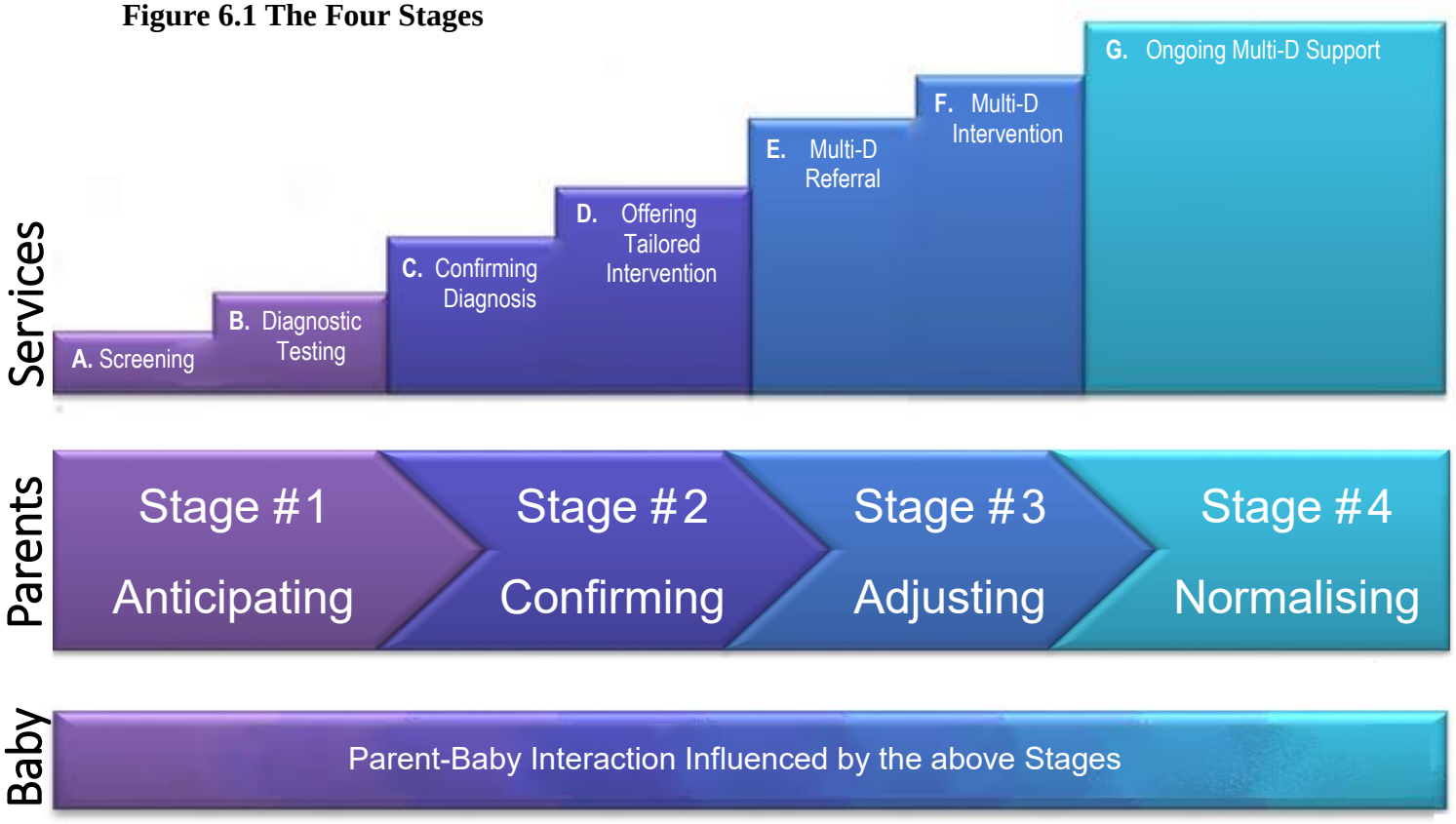
6.1 Overview: The Four Stages

The analysis data revealed that the parental experience of receiving an early diagnosis of their child's hearing loss in Ireland, can be characterised into four overarching and distinct stages:

- Stage #1 Anticipating
- Stage #2 Confirming
- Stage #3 Adjusting
- Stage #4 Normalising

The stages are consecutive, and synchronise with the corresponding point of service provision. The parent's journey through the distinct stages also influences their interaction with their newborn baby. The diagram below depicts this conceptualisation.

Figure 6.1 The Four Stages

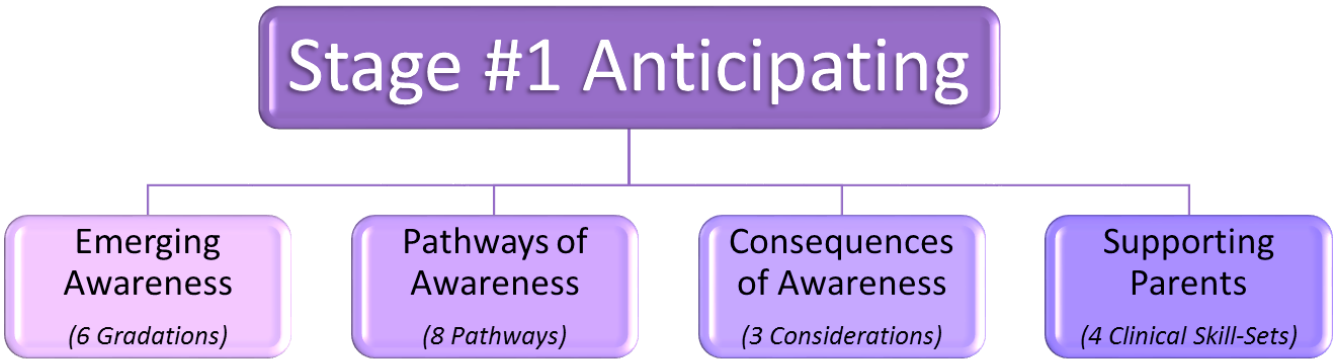


Although these stages are sequential, they do not represent a uniform experience. The ensuing chapter will present the diversity of parental experiences within each stage. The significance of journeying through these four stages cannot be underestimated. One parent stressed "I will never forget that whole period of time" emphasising, "I can vividly remember every bit of it" (*ITC – Interview Transcripts Compiled*, p.31: 19-20). As this research is focused predominantly on the parental perspective, this chapter will primarily be considered from their vantage point, examining each of the four unique stages in turn.

6.2 Stage #1: Anticipating

Stage #1 is defined by the anticipation of parents as they await a diagnosis. This stage is initiated by the first failed hearing screen (typically conducted in a maternity hospital) and concludes with the penultimate diagnostic appointment (typically undertaken in an audiology clinic). The majority of parents in the sample described entering into Stage #1 with no anticipation that a hearing loss was even a possibility for their child. Consequently, this initial stage is characterised by a growing sense of anticipation as the possibility of a hearing loss becomes increasingly probable with each successive appointment. As illustrated by the diagram below Stage #1 encompasses four sub-categories each of will be explored in turn.

Figure 6.2 Overview of Stage #1



6.2.1 Emerging Awareness

With no family history, experience, or exposure to hearing loss, the possibility of PCHI never even occurred to the majority of the parents in this sample. One parent expressed that

> When [my baby] was born, she got the test that day actually, and … they kind of couldn't get a response or whatever… [but explained] it really could be that there is fluid because she kind of came so quickly, so am. That was grand. And then they redid, they did something else the next day… and again they couldn't get a response I think was the term or something so. We kind of didn't worry that much about it then ...I knew no one with a hearing loss, or knew nothing about it…when you know you're pregnant, we all think of…a lot of different disabilities, but for some reason, am, this was one I never thought of…. [the public] health nurse and my parents and everything [were pointing to my baby] saying "look at her she's so alert you know"... she really was following everything….we'd think she'd react to noise,… So we genuinely didn't think there was a problem (*ITC*, p.119: 10-29).

The initial realisation that their baby may have a hearing loss occurred at different points for different parents, and developed with varying forcefulness over the course of diagnostic testing. The table below captures different gradations of awareness which parents experienced during Stage #1.

Table 6.1 The Emerging Awareness of Parents during Stage # 1

Gradation	Explanation	Quotation
No Awareness	No suspicion of hearing loss	I had been told about the neonatal screening at one of the anti natal appointments, and then completely forgotten about it. So they came around to check [my baby after birth], and I said ya go ahead, they told me he had failed it and I sort of felt it's a screening test, am, didn't put an awful lot of (feeling) into it to be honest. … I didn't know very much about them at the time…So they did three separate screenings, chances to pass it ((laugh)), in the hospital. And then, by that stage, am, we were told, look you'll get an appointment in the post, and we kind of went home and forgot about it really (*ITC*, p. 173: 5 - p.174: 7). The kind of perception out there was because it was new, am it's often, kind of unreliable, that you know anecdotally everyone knew people that you know, children were screened and you know gave a, they couldn't get a result, and then they were fine or whatever. So it's funny, I had heard of the test but kind of with this view that it might not work or you know, just don't be too worried about it (*ITC*, p.119: 5–9).

Reassured Awareness	Suspicions are eased with reassurance	They came around to do the test, and there was a little, as I said, am, fluid in her ear, so the girl who did the test was very nice and she said it has happened before. Sometimes it can be to do with the birth, and they come back again to do another check on her. So you know she went away, I suppose, it was in your head but you didn't panic straight away about it because she was very reassuring as well (*ITC*, p.104: 6-10). They had to do [the screening] every 24 hours for the first few days, she kept on saying "look, it could be just nothing, it could just be fluid" and stuff like that. So that's just what we went for (*ITC*, p.50: 30-32).
Confused Awareness	Recognise an issue but experience confusion	She'd to be asleep for that [first diagnostic] test. So. Once again there was still a concern….and we were a bit unsure, because I suppose we were asking the questions, well, what does this mean? And what's the plan now? (*ITC*, p.104: 18-21). That department, or that team is very good… in fairness now they were on the ball, going for testing. Literally, it's very confusing. Do you know what I mean, like you know, it's very confusing. And they were trying to explain to me, the high pitch, the low pitch, the frequency, and you know, all this, and I was saying, that's one thing alright, it's very confusing, and a little bit hard to understand (*ITC*, p. 225: 23-28).
Growing Awareness	Increasingly discern there is some form of hearing loss	I think the first time alright [in the diagnostic appointment], there was some term like inconclusive or something that…maybe there was a suggestion of [a hearing loss]… Because I remember my husband and I came out and were like ((realizing tone)) "hmm, ok that's it so"… I don't think at that stage I had much of a doubt (*ITC*, p.123: 39 – p.124: 2). Now when they did that [diagnostic] test… she was saying, look, "no, there's like a serious hearing loss here like"… then I suppose there was alarm bells because I was saying "is he deaf or what?" do you know what I mean, because nobody wants that for their child or whatever you know. So then back again for further testing but it was improving all the time (*ITC*, p.229: 32-36).
Acute Awareness	Fully aware that there is a PCHI.	Like we kind of knew, I was holding him in my lap we was sound asleep, and I could hear was, at one stage I could hear the noise from the probe which was obviously in near his ear drum but he was sleeping peacefully, so I kind of knew at that stage he was profoundly deaf because you know he should have been hearing that ((laugh)) (*ITC*, p.174: 24-28). [My spouse was] testing her all the time, saying ((excited voice)) "She's turned, she's turned". And I said "no she's deaf. Forget about it. She's deaf like. I just know it" (*ITC*, p.34: 28-29).
Chronic Awareness	Preoccupied by anxiety / the worst case scenario	I was thinking the worst…I remember, obviously having a real cry someday. And my husband saying, "no, no, no, it could be the opposite too, it could be really mild". And I was saying, "no but it could be really profound." Unfortunately, I as the mother was thinking of the worst case scenario (*ITC*, p.155:7-21). [My baby didn't] pass the first test, so he has second test, third test, different kinds of test to confirm. That's a very hard time for parents ((weeps)), °very hard time° ((weeps)) (*ITC*, p.1: 28-29).

This table classifies the maturation of parental awareness, capturing the development from no awareness, to reassured awareness, to confused awareness, to growing awareness, to acute awareness, to chronic awareness. While these gradations are presented consecutively (for the purpose of clarity), it is critical to emphasise that parents do not all necessarily begin at the same point of awareness. For example, while the majority of parents began their journey with *no awareness*, a minority awaited the first hearing screen with *growing awareness* (the reasons for this are discussed below). Furthermore, as evident in the quotations embedded within the table, these different gradations of awareness are correlated with different events for parents. For example the initial failed hearing screen (with the accompanying explanation) precipitated *reassured awareness* for some parents but *acute awareness* for others (this is explained further in the following section). It is also important to highlight that parents do not necessarily experience each level of awareness outlined in the table, feel only one at a time, or rise through the successive levels of awareness sequentially. Thus, while the previous table is helpful in succinctly depicting the subtle gradations of awareness, a number of alternative pathways through these gradations were observed as participants described varying experiences of Stage #1.

6.2.2 Pathways of Awareness

In particular, eight alternative pathways of parental awareness were documented in this research as participants articulated diverse experiences of Stage #1. These pathways are outlined below.

a) Gradual and Growing Awareness

Parents within this pathway described a gradual increase in awareness over a number of successive appointments. Parents gently transitioned from having no awareness to a reassured

awareness to a confused awareness to a growing awareness and, finally, to an acute awareness. These measured transitions were prompted by the clinician gently giving information by increments at appropriate stages, and the parent's own reading of the circumstances. In reflecting upon this experience, one parent expressed

> I'd been telling myself it was fluid in the middle inner ear was the problem. So [after the audiologist got the initial results] she said, look we won't interpret that until we've done the test again. So that put a doubt in my head, it was obviously a level of hearing loss, but I suppose we'd always been given the hope that it was a middle ear problem and that a grommet would fix it. So that was, in fairness to [the audiologist] I think it was the best way of dealing with it, rather than saying "I don't think it's the middle ear" but giving you the possibilities of the two diagnosis. So that sowed the seed for us to kind of come to terms with a possible diagnosis [of PCHI], which was a nice way of doing it, because giving a diagnosis, it can be easily to be too abrupt and so on, so I brought [my husband] with me the next time, and they did the full blown testing, and at that stage they told us, yes there is a hearing loss, and it doesn't look like the middle ear. And they showed us the audiogram (*ITC*, p. 189: 17-26).

This approach gently prepared these parents to receive a diagnosis, which was eventually given in the context of expectancy.

b) From Unaware to Critically Aware

This pathway encompassed a sudden leap from a reassured awareness (that it could just be fluid) to a chronic awareness (of the worst case scenario). One parent explained that this swift transition occurred during one appointment, and described "I kinda started freaking out, because I though the fluid, obviously, it can't be" (*ITC*, p.51: 2). This parent's previous reassured awareness quickly matured into a chronic awareness as she learned her baby could have a profound hearing loss. This abrupt leap in awareness, coupled with an anticipation of what she perceived to be the worst possible outcome, caused this particular parent to be crippled with anxiety.

> So there was one time we went up there and they thought he was deaf in the two ears…they sent us home one Tuesday evening thinking that he was totally deaf, which was awful, just awful, because he'd to go back then the following Thursday to get more tests. So for two days then we thought we had a [profoundly] deaf baby, we really did (*ITC*, p.46: 8-11).

The period of waiting for the final results was particularly distressing. This parent was left with an unconfirmed prognosis and no understanding that interventions would be available in this predicament. The prognosis transpired to be inaccurate which seemed to cause the parent unnecessary anguish. Interestingly, another parent in the sample experienced the same prognosis of a profound hearing loss during Stage #1 which was later refuted. However, in contrast to the previous experience, they felt this fostered preparation rather than unnecessary distress, and appreciated the transparency:

> I suppose, by them telling me its severe, you are kind of preparing yourself…if it improves, its great news for you, rather than saying "here we are, it could be mild but it might be worse", I think your better of saying "it's worse" and then [it improves] you know do you understand me? (*ITC*, p.225:32-35).

c) Acute Immediate Awareness

A predisposed and sophisticated level of awareness was evident with parents who already had an older child with a hearing loss[18]. This specific group of parents highlighted an acute awareness with the first failed hearing screen in the maternity hospital:

> I'm sure that that girl told me, it may only be fluid, it may not be anything, but you know what, she could have said that a thousand times to me, but the minute I saw that test being done, and knowing the baby had failed it, ya, I had decided there and then, ya this child has a loss. And that would have been one of the hardest times (*ITC*, p.156: 13-17).

[18]An immediate incisive awareness was also highlighted in cases of babies born with visible abnormalities to the ear rendering the certainty of a hearing loss immediately apparent. In this rare predicament, parents bypass the anticipation of Stage #1 as the certainty of the outcome is immediately present. However, the family still goes through the process of diagnostic testing which defines the chronology of Stage #1.

The parent expressed "I left the maternity hospital with no doubt that the baby had a hearing loss" (*ITC*, p.153: 36-40). As a consequence of interpreting the screen as a diagnosis of hearing loss (regardless of the screener's professionalism and reassurance to the contrary), these parents found the process of newborn screening in a public, rather than a private, environment particularly upsetting. One set of parents explained

> You're sitting in an open public ward when they are actually doing the [newborn screening] test, which is, it's really not appropriate…. And [the lady] says 'oh no, we need to repeat the test because-' you know she didn't use the word failing it, but I automatically said "ok, look that's it".…Now but they were saying, "no, no, no" absolutely, they were very nice…they did it in a very professional way and I think if you weren't, if you weren't, if we weren't conditioned, we probably would have thought ok ya ok, and we probably would have moved on…[but] the environment wasn't right… Because I mean, you're trying to keep the baby quiet, you're trying to keep the baby still, there is a lot of noise around, is it the right environment to do it? Not I would say (*ITC*, p.25: 14-31).

Another parent in this predicament described that "it certainly is not the nicest place to be told" (*ITC*, p. 165: 3-4). This parent also found that being alone during the screen, rather than having a supportive spouse, partner, or companion present, to be very lonely. In addition, the period of waiting for successive appointments, and ultimately the final diagnosis, was particularly agonising due to their heightened awareness. As the parent expressed "I wanted answers at that stage. I needed, I needed, I needed a level [of hearing loss]" (*ITC*, p.157: 9-10).

d) Sensitised Awareness

Parents in this sample who experienced multiple diagnoses (affecting the baby's cognition) had quite a different experience of Stage #1. Due to the overwhelming number of complex medical concerns surrounding the baby, these parents were more sensitive to the implications of the failed screen, and less comforted by the ample reassurance offered:

> She didn't say there was a loss, she said that, she, the child wasn't responding in that ear…and she was explaining that it could be fluid. We didn't take that 100% on board, we thought ((worried tone)) "oh here we are again now, they are letting us down" do you know that sort of a way, they kind of drip feed you the, that sort of way, so we weren't reassured by that at all. Now I know with some babies that isn't the case at all, but that was just us, we were just very negative at the time anyhow (*ITC*, p.221: 6-12).

While these parents articulated that the potential hearing loss was the secondary rather than the primary concern, the failed screen was yet another potential complication they had to confront. They expressed that this added to their distress and to the complexity of the child's diagnosis.

e) Preoccupied Awareness

In contrast with the previous pathway, other parents dealing with the potential of serious medical complications (arising from prematurity, admittance to the neonatal intensive care unit, multiple births, additional diagnosis, etc.) described a preoccupied awareness during Stage #1. They described that they did not dwell on the hearing loss exhaustively or exclusively, as it was overshadowed by more pressing concerns:

> Because they had listed out all these other complications that she could have, and I was like 'oh my God', so the ... [concern surrounding her] ear was minor in comparison to those you know, so not to say that we didn't care about that, but was just that the other things, if they were wrong, were going to be potentially more serious for her…So in the scheme of things, it was a smaller, it was just one of many things that was going on at the time, you know (*ITC*, p.235: 12-26).

It is important to highlight two factors influencing this pathway. Firstly, the two families articulating this position experienced the retrospective relief of these additional complications being refuted rather than confirmed. Secondly, these families also had previous experience of hearing loss, rendering it less of a fearful unknown. Thus, while hearing loss was still significant, it was not necessarily of primary concern to parents at this point[19].

[19]Significantly, two families in this sample described that having other children as also fostering this sense of a preoccupied awareness.

f) Grounded Awareness

Some families who experienced the flux of a changing prognosis expressed that, although feeling shocked, fearful, and worried as they anticipated a hearing loss, they found it essential to remain grounded in the present, rather than entertaining unconfirmed and distressing possibilities:

> I was just taking every test as it came do you know what I mean? Saying "look the results today will be whatever and we will just deal with it"...That's just my attitude…And I really didn't think too far down the line either. Because sometimes I think if you do that, you kind of stress yourself out over, you know, things you needn't be stressing yourself out over, do you know? (*ITC*, p. 224: 5-26).

These parents recommended taking the diagnostic process one step at a time, and emphasised the futility of worrying about possible outcomes which may never transpire. This grounded approach continued into later stages of their journey as parents continued to deal with ongoing uncertainty.

g) Bewildered Awareness[20]

A minority of parents seem to retain a low level of awareness throughout the entire process of diagnostic testing, despite verbal and circumstantial indications to the contrary. While it was common for parents to experience a *confused awareness*, a minority of families appear to present as bewildered, and the successive explanations and evidence of the increasing probability of a hearing loss does not seem to register with them. This response seems to be a defence mechanism to protect themselves from the distress of acknowledgement. Unfortunately these parents are unlikely to be prepared for the impending diagnosis.

[20] This description featured in a section of the transcript that the researcher did not have permission to cite.

h) Circumspect Awareness[21]

Some parents appear to react to the increasing indications of a hearing loss with a sense of circumspection and misgiving, and seem to question the validity of the testing and results. Although extremely rare, this may potentially continue to the point of rejection.

6.2.3 The Consequences of Awareness

It is important to highlight that these eight trajectories were specially observed in relation to an *early* diagnosis of hearing loss in Ireland. Parents with older children described two further trajectories unique to a *later* diagnosis which are outlined in the footnote below[22]. Furthermore, while these eight trajectories of awareness are distinct entities, some families experienced more than one simultaneously. Regardless of which pathway a parent travelled through, the increasing anticipation of Stage #1 engendered two repercussions for parents, and one subsequent challenge for professionals. These three consequences are explained below.

a) Anxiety

Firstly, the analysis of data indicates that the increasing awareness of Stage #1 is typically (but not universally) correlated with increasing parental anxiety. Parental anxiety encompasses a flood of strong emotions including feeling stressed, afraid, confused, guilty, lost, uncertain, nervous, worried, devastated, upset, helpless, frustrated, and impatient. One parent expressed:

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[21] This description featured in a section of the transcript that the researcher did not have permission to cite.

[22] Parents with older children with PCHI experienced the following two trajectories specific to a late diagnosis:

- **Abating Awareness**
  Although the parents initially suspect a hearing problem, the child's remarkable compensation camouflages any lingering evidence of a hearing loss. Consequently, the parent's early suspicions are abated. When the child is eventually referred for diagnostic testing, the parents believe there is just a middle ear problem, and neither suspect, nor anticipate, the possibility of a significant hearing loss.
- **Independent Awareness**
  Other children exhibited clear signs of a hearing loss over a number of years. The parent independently came to the conclusion that the child had a hearing loss, but encountered professional denial in seeking a diagnosis.

> It was my husband who was holding her when she was having all the tests done and I was just sitting there, am, just wishing that it would all go away ((sad laugh)), I just remember the time thinking, "how did this happen to us? What did we do?"…I remember I started going back over the whole year when I was expecting her...But there is nothing you can do about that when you are sitting in there (*ITC*, p.214: 7-14).

Anxiety can also be augmented by the process of diagnostic testing itself, particularly if the results are prolonged, or if the baby is not sleeping long enough to complete the ABR assessment. As another parent explained, "there was a certain amount of stress to it, because you almost felt like it was outside of your control, you would only do so much" (*ITC*, p.151: 34-35). Parents who reached a chronic awareness during this diagnostic process experienced acute distress:

> Actually ((weeping)) the hardest time is not to accept this, the hardest time is waiting for the result…The test time is the horrible time ((weeping)). The worst time for parent ((weeping)) (*ITC*, p.8: 6-10).

Parents who reached this level of anxiety desired the results as quickly as possible to end the distress of the unknown. The participant check corroborated these parental responses as 100% of parents either agreed (71%) or strongly agreed (29%) that the "description of anxiety while waiting for a diagnosis is appropriate" (*PCS - Participant Check Spreadsheet*, q.3).

b) Preparation

Although the increased awareness of parents typically fosters anxiety, it can also engender anticipation, preparing the parents to receive a confirmed diagnosis in Stage #2. This is crucial when the possibility of a hearing loss is a "bolt out of the blue" (*ITC*, p.173: 3). One parent articulated that the audiologists' verbal explanations over a number of appointments created a sense of context and gradual recognition which in turn caused her to affirm that

> The diagnosis was given well I thought…it was a step-wise process, and I suppose recognising and accepting the problem you know… I mean if they told us, the day after [my baby] was born that he was deaf, I don't think we'd have believed it (*ITC*, p.189:26-29).

The same parent reflected that the circumstance of successive testing also precipitated an increasing sense of expectation, which meant that "the day we got the diagnosis we were kind of half prepared for it, because we'd sort of copped something was wrong ourselves" (*ITC*, p.188: 40 – p.189: 2). While this preparation did not tend to remove the parent's shock, it appeared to soften it. In contrast, parents who block out any sense of awareness during Stage #1, despite verbal and circumstantial indications to the contrary, do not seem to develop a sense of anticipation for the forthcoming diagnosis. Subsequently, Stage #2 appears to be more shocking for these parents. Thus, while this increasing sense of anticipation typically incurs anxiety, it also appeared to provide a crucial preparation for an impending diagnosis.

c) Balancing the Anxiety and Preparation

The clinicians supporting parents through Stage #1 of their journey face the precarious challenge of cultivating anticipation but curtailing anxiety. Analysis of data revealed the need to guard against both extremities of an abrupt diagnosis (without any prior preparation), or a delayed diagnosis (with a prolonged period of anxiously waiting). The timing of information appeared to be crucial in this consideration. Parents with a low level of awareness seemed to be receptive to receiving information by increments to foster preparation. In contrast, parents with a high awareness described being amply prepared and desired as swift a diagnosis as possible to end the distress of waiting. Thus, the clinician's capacity to tune into the parent's level of awareness seems to be important in enabling the clinician to discern how to foster anticipation but restrain anxiety. Within the participant check 86% of parents[23] either agreed (29%) or strongly agreed (57%) that "it is the audiologist's role to prepare parents to receive a diagnosis" (*PCS*, q.4).

[23] Interestingly, a minority of 14% parents neither agreed nor disagreed with this assertion, and indicated their sense of uncertainty with the explanatory comment that audiologists are "not trained for this?" (PCS, c.3). The question of adequate training is an important issue which is addressed in the Discussion Chapter.

6.2.4 Supporting Parents

The clinician's capacity to balance these needs and support families though Stage #1 of their journey appears to requires significant discretion and discernment. The analysis of data revealed that the clinician needs a range of expertise to navigate the diagnostic process supportively. In particular, the following four skill-sets were identified as crucial.

a) Adept Clinician

Firstly, the data suggests that the professional needs to be an adept clinician procuring an accurate diagnosis. Parents depicted clinical proficiency as a priority and expressed that they "didn't kind of mind doing all this testing" because ultimately they wanted a result that was as "clear" and "certain" as possible (*ITC*, p.156: 30-33). Consequently parents expressed

> They were very much all the time, business kind of, but that worked, you know, ya I prefer them, because it takes hours those tests...like literally hours…I just prefer them to be totally, just do your job, just get the diagnosis and we'll kind of do something about it (*ITC*, p.124: 4-12).

During this diagnostic endeavour, parents appreciated the professional expertise and "authority" to "back it up" (*ITC*, p.188: 6-8). This appeared to engender a sense of trust and confidence in the accuracy and reliability of the clinician's diagnostic assessment.

b) Lucid Communicator

Secondly, the professional capacity to communicate lucidly was also identified as important in the data. Parents with no background in audiology emphasised "it's very confusing, and a little bit hard to understand" (*ITC*, p.225: 27-28). As a consequence, as one professional explained, the audiologist's capacity to explain complex information in an understandable capacity appeared to be an essential skill:

> The ear is a complicated system, and there are many pieces of it that you have to understand am, and I think, confusion comes because parents very often aren't, you know, they are not audiologists so… they are not coming with an understating of how the ear works, or how the different components are tested as well…so I think, they are confused…. And the confusion about what's done, what's to come, what test refers to what part of the ear, is it an inner ear problem, is it a middle ear problem, is it a big deafness, is it a small deafness, what does deaf mean, can you hear anything. So it's just a very confusing time and [the audiologist's] role… within that particular feeling of confusion, is to support parents….making information as clear as [they] possibly can, and [they] use diagrams quite a bit which I think are really useful (*ITC*, p.195: 30 - 196: 5).

This ability to translate complex information into "plain English" was consistently identified as crucial (*ITC*, p.57: 19).

There was disagreement among participants as to whether the clinician should offer parents unconfirmed indications of the exact level of hearing loss during Stage #1.

> From the professionals point of view, they almost have to give you the worst case scenario, I think that's, from day 1, I think that's what they gave us. And I don't, I wouldn't disagree with that practice, I suppose, maybe it's better to be told the worst case scenario and things get better after that. Other people would probably argue it's better to be told gently, and when you cope with that maybe you can cope with "actually maybe it's worse…" I think they tell you as they see it, and they don't, they don't try to hide it (*ITC*, p.151: 6-11).

As described in section 6.6.2(b) this level of transparency provoked disagreement as some parents felt it created a sense of preparation, while others felt it caused unnecessary distress.

Significantly, the same debate occurred among parents who experienced a more gradual explanation of the results over successive appointments. As described in section 6.2.2 (a) some families greatly valued this gentle approach, and appreciated the care and discretion it represented. In contrast, another family (with a prior history of hearing loss) did not need this level of sensitivity. They explained:

> I think they did that [diagnostic test] twice. So the first time they did it, it was confirmed. But they were being very, am, cautious in telling us, but again we were looking at the results, we were clued in, we said, "look she's deaf" and they said "no, no, no, no" we need to go check it again…. we got the senior audiologist in, the next time we were in…and it was reconfirmed (*ITC*, p.26: 24-34).

Thus, it was clear from the research that different parents preferred different blends of transparency and discretion in the communication of unconfirmed results.

c) Judicious Coordinator

Thirdly, the analysis of data suggests that the clinician needs to be a judicious coordinator, organising their services to suit the needs of families. This family-centred coordination was important, particularly if the baby was not sleeping through the diagnostic testing. In this stressful predicament, parents expressed their appreciation for audiologists who "showed a lot of empathy", and emphasised that it "<u>does</u> make a difference" when the clinician understands that a newborn baby has an unpredictable sleeping routine (*ITC*, p.164: 6-11). The clinician's foresight to coordinate the appointment with these needs and stresses in view was important

> So they'd recommend to go away and give her a feed, or take her for a walk, and try and get her into as deep a sleep as possible…and sure babies being babies she could be asleep coming back to the door and she could be awake two minutes later again (*ITC*, p.151: 20-32).

Furthermore, parents also appreciated (and recommended) short waiting times between appointments to minimise the distress of waiting. The clinician's ability to recognise these needs and coordinate their own *internal* services (to their best ability within the limitations of the healthcare structure) appeared to be essential. In later stages their *external* coordination skills are also important in directing the referral process and engaging with a wider multi-disciplinary team.

d) Compassionate Counsellor

Finally, as one parent articulated, the clinician also needs to be a compassionate counsellor, empathetically supporting the parents during an acute period of vulnerability:

> They need to [show] concern … [for] the parents' emotions as well ((voice breaking with emotion))…the dialogues [and conversations with the clinician], they are very important because we just talk to them in the beginning, just see them in the beginning…if they could pass their care ((voice breaking with emotion)) to the parent, that would be a lot better. Not just the result (*ITC*, p.9: 10-16).

The majority of participants concurred and greatly valued their clinician's empathy, gentleness, and sensitivity. The data therefore revealed that a good parent-professional rapport and emotional support should permeate the entire diagnostic process before, during, and after giving the diagnosis. However, it's important to acknowledge that one participant articulated a different perspective:

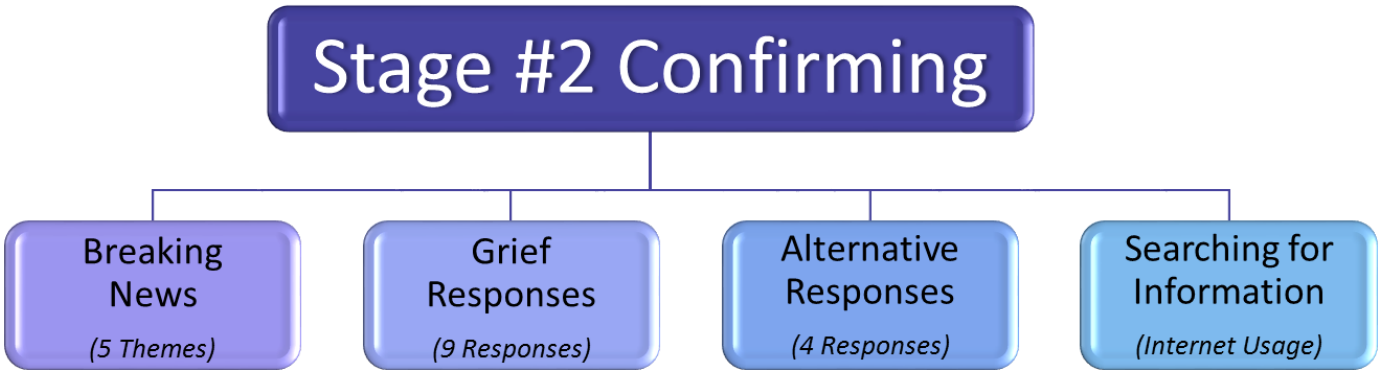
> I just prefer the fact that they were…<u>really</u> doing their job, rather than just sitting around and mopping up my tears, do you know? That wouldn't have worked for me (*ITC*, p.124: 9-10).

Consequently, it was clear from this discrepancy that the clinician needs to exercise discretion in ascertaining what extent to engage with the parent on an emotional level as they prepare for, and later receive, a diagnosis. Significantly, even this intuitive judgement represents a counselling skill.

6.3 Stage #2: Confirming

While Stage #1 encompasses the increasing anticipation of families as they await a diagnosis, Stage #2 consists of the confirmation and communication of the diagnosis to the parents. As illustrated in the diagram below, Stage #2 consists of four sub-categories, each of which will be examined in turn.

Figure 6.3 Overview of Stage #2



6.3.1 Breaking News

The professional's communication of the confirmed diagnosis was a pivotal experience for many parents. The following five specific themes were documented in interviews.

a) Manner of Delivery

Parents had different preferences for what they appreciated in how the final diagnosis was communicated to them. One parent emphasised:

> What I really appreciated was them saying kind of over and over again, "significant hearing loss". And that was the term, which you think sounds really horrible, but I think the important thing is they have to be really clear (*ITC*, p.121: 3-6).

This parent appreciated the very clear, direct, and clinical approach in delivery and did not want to be emotionally comforted by the clinician. In contrast, (as highlighted in Stage #1)

other participants valued a very compassionate approach, emphasising the importance of an empathetic delivery given with emotional support. Yet another parent appreciated the blend of both the clinical and compassionate approach articulating, "We just liked her style, she was very straight but very supportive" (*ITC*, p.188: 5-6). Thus, it was clear that delivery needs to be tailored, not standardised.

b) Detail in Delivery

The amount of clinical information parents desired (at this stage and beyond) differed significantly from parent to parent. One parent expressed:

> I really only wanted to know what they told us in layman's terms, rather than actually understand the actual testing…I almost ignore that information and just skip forward to, ya, I trust you know how we've come to the conclusions, I just need to know the conclusion (*ITC*, p.158: 18-30).

In contrast to this perspective, another parent articulated:

> I just love the fact that it's a science and you can kind of see you know if it worked, if they got am reliable results you have an audiogram at the end of it kind of, and you can compare it and you can see what's going on. You know it really does help (*ITC*, p.135: 31-33).

However, despite different preferences for clinical detail, parents consistently valued explanations in colloquial terms. As one parent explained, "in fairness to audiologists… [they] explain everything to us in bog-standard language which was great because I know nothing about audiology (*ITC*, p.180: 6-8). Parents also recommended not overlooking the most obvious and rudimentary information, stressing "I knew no one with a hearing loss, or knew nothing about it" (*ITC*, p.119: 17).

c) Offering Hope

Parents consistently stressed the importance of being offered hopeful interventions alongside the confirmation of diagnosis.

> I think it was handled quite well… [The diagnosis] was, broken gently and then we were given the options straight away, they came straight in with the hearing aids and the cochlear implant information. So that was kind of nice. We am, we weren't left with this awful diagnosis, and no kind of way out of it, they were immediate with their interventions (*ITC*, p.189: 3-5).

Hope was offered not only in the form of intervention, but also in presenting a positive perspective of hearing loss. Many parents in this sample found great comfort and relief in this perspective, particularly during Stage #3. However, one exception was noted. In the experience of one family with multiple-diagnosis, the clinician's well-intentioned but misguided challenge of a hopeful perspective was not applicable due to the specific medical complications the child had. Consequently, the experience was more hurtful than helpful to these parents who felt undermined in their grief. Thus, offering hope requires gentleness and discretion, particularly at vulnerable stages and in complex cases.

d) Time

Parents greatly appreciated when time was given to them in important appointments, not only with the audiologist, but also with the wider multi-disciplinary team (in the case of a more complex diagnosis). One parent expressed:

> He was just, so sweet you know, he just really took the time, like there was no "I've 700 people to see today", kind of thing, it was "I'm here now to see you, and I'll be here for as long as you want me to, and if you have any questions, give me a call"…there was no such thing as rushing us, he really took the time to go through it with us, you know, which makes a big difference (*ITC*, p.240: 22-26).

Parents were very receptive to this provision of time, accessibility, and availability, which engendered a tremendous sense of being supported.

e) Retention of Information

The issue of retention repeatedly arose in interviews. Many parents described that as a consequence of overwhelming emotion, they struggled to absorb information, no matter how clearly it was presented. One mother expressed, "to be honest I just °pretended that I knew what she was talking about°" (*ITC*, p.212: 25-26). Likewise another parent described "all I took from it was significant hearing loss, and again, I knew nothing at all. So I didn't know what that meant or anything" (*ITC*, p.120: 9-10). Another family described being so stunned in the appointment, that they did not feel the full force of the news until they got home:

> You are a bit like a dummy when you are being told. You know. You're kind of ((mouth wide open with shock)) ((laugh)), and then you come home and the, the questions flow do you know (*ITC*, p.109: 19-21).

The parent explained that "in that little window" it would be helpful if "maybe if there was somebody there to talk to you that would have more time" (*ITC*, p.105: 15-16). Thus, immediate follow up support for the family was identified as crucial. In addition, another parent strongly recommended that having a second, supportive person present with the parent during the appointment to absorb the news. They explained that this would be helpful

> even just to take in the information, because it is because it is technical, it is jargon that you will not have heard before, and am, just to be able to, if it is your partner or mother or whoever it is, it's just afterwards on the way home or whenever, the following [day], if someone else even asks you, God I'm not too sure maybe he knows, or she knows. Do you know what I mean, it's another pair of ears listening in (*ITC*, p.167: 2.6).

6.3.2 Responding with Grief

In receiving and responding to the diagnosis, hearing parents, with no prior exposure to hearing loss, experienced acute grief. This encompasses a plethora of strong thoughts and emotions. As the words of parents carry the most powerful expression of this experience, their own descriptions will govern this section. The following table compiles their depictions.

Table 6.2 Responding with Grief

Response	Quotation
Shock	Once we got the diagnosis, that was a bit of a bombshell (*ITC*, p.177: p.2-3). You are a bit like a dummy when you are being told. You know. You're kind of ((mouth wide open with shock)) (*ITC*, p.109: 19-20).
Disbelief	It is a very hard time for parents because…our family have no family history [of hearing loss], and then when the hospital diagnosed it, it's like I can't, no, no I just can't believe it… It is a very tough time at this stage...At the beginning its very hard to accept (*ITC*, p.1: 5-8).
Numb	I'd say like that weekend. We were just numb. Absolutely numb (*ITC*, p.34: 19). My brain was ((voice breaking with emotion and starts to weep)) empty on the first three months (*ITC*, p.2: 18).
Anger	You'd be angry that it happened to your child and it happened to your family *(ITC*, p.219: 2-3).
Guilt and Blame	[I felt] very guilty, I don't know ((weeping)) like every time we go to see any kind of doctor ((weeping and inhale)) I can't control my emotions. I say, what … [caused] it, I mean, did I do anything wrong during the pregnancy like ((weeping and inhale))… You feel very guilty, especially the mum ((voice breaking with emotion)) like… you don't know what have you done wrong ((weeping)) to cause it (*ITC*, p.5: 6-19).
Lost and Overwhelmed	At the start we didn't have a clue, I swear to God, we were saying "oh my God now, how are we going to deal with this" (*ITC*, p.228: 22-23). I think, we were kind of lost at the beginning because you know the terminology even is something we weren't familiar with (*ITC*, p.121: 34-35).
Sadness	It was just absolutely dreadful. I was nearly ready to burst into tears the whole time. Absolutely dreadful *(ITC*, p.30: 21-22). I [was] crying every day on the first three months ((weeping)) but it takes time to ((sniff)), to adapt like ((weeping)) (*ITC*, p.2: 25-27).
Loss and Devastation	Your whole world falls apart because you, you eh, you know something, you might as well have been told your child has just died. Really. It's as bad as that right. Now looking back now, and what I'd say to parents, is "look it's not the worst thing in the world"… but when you are told that at the time, and you don't have deaf people in your family and you're not deaf, it's devastating, it really is (*ITC*, p.30: 4-9).
Worry, Fear and Stress	My worry was, is this part of a big syndrome, or is this an isolated hearing loss. That was the one thing that I found a bit stressful at the beginning (*ITC*, p.173: 27-30). Like you worry about…their future, whether they will have a normal lifestyle, everything ((weeping)). You are thinking a lot ((voice breaking with emotion)) about what way the baby will be (*ITC*, p.5: 27-29). We didn't know what kind of future she would have. Would she be able to speak, would she go to school? (*ITC*, p.15: 2-3). What's going to go crazy is imagination and fear (*ITC*, p.96: 26-27).[24]

[24] All the quotations in this table are from parents, apart from this final one which was from a professional

As evident in the above table, parents reacted to the diagnosis with shock, disbelief, anger, guilt, blame, sadness, loss, devastation, worry, fear, and stress and they also described feeling numb, lost, and overwhelmed. These overpowering responses often engendered acute emotional vulnerability. The summation of these diverse responses as *grief* arises from the descriptions of participants themselves who depicted their experience as "mourning" (*ITC*, p.34: 16). These painful emotions did not occur in a sequence and were not all experienced by every parent. While grief will never dissipate completely, the initial intense emotional force of grief (which was particularly raw in the wake of the diagnosis) endured for very different time-frames for different parents in this sample, varying from a few weeks to six months. In addition, parents experienced many of these emotions simultaneously, with varying force. Thus, parental experiences of grief were unique and varied.

It is important to highlight that parents in this sample who received multiple-diagnoses articulated a compounded sense of grief and loss. As one parent emphasised:

> Having additional needs, makes it 100 times worse, than if it was just the hearing loss… I suppose I was traumatised, as it was because I had just had her, and am, on top of the ears, we had [additional medical complications and the possibility of surgery]… so we knew we would have to go through all that and that would be happening in a couple of weeks' time…so it was just a huge, a lot to take on board (*ITC*, p.213: 34 – p. 214: 6).

This parent explained that the many losses were not differentiated but subsumed under one response. She expressed that "it was quite devastating… it was all kind of mixed in together with the whole diagnosis" (*ITC*, p.212: 4-5). Parents in this predicament articulated "I don't know if we'll ever 100% get over the whole experience" (*ITC*, p.219: 18-19).

6.3.3 Alternative Responses

While the majority of parents articulated their experiences of grief, a minority of parents described a very different set of emotions which were remarkably hopeful and positive. These alternative responses to the diagnosis are captured in the following table, with the rationale explained in the parent's own words

Table 6.3 Alternative Responses

Response	Quotation
Disappointed but Prepared	It didn't come as a major shock to us because the family history was there, but at the same time it was a huge disappointment (*ITC*, p.144: 15-17). Of course I'm disappointed, of course I was upset. But we kind of prepared ourselves for it (*ITC*, p.34: 25-26).
Hopefulness	Here we were faced with a baby who had a loss, that wasn't going to be as bad at all as her older [sibling] and was being diagnosed at days old, relative to [her sibling] being diagnosed [so late]…so everything was in her favour…that took a lot of the worry out of it (*ITC*, p. 149: 32-36). So we were saying, at least now it's picked up now for [our baby], when he is so young, and he can get the help that my [deaf family member] missed out on (*ITC*, p.224: 34-35).
Thankful and Relieved	We were upset but at the same time it was a bit of a relief to get the diagnosis. I think we just realised how fortunate we were to have the screening…I think that [a late-diagnosis with a toddler] would be 10 times harder than finding out you have a deaf baby (*ITC*, p.177: 2-10). In the scheme of things that could have been wrong…it was more like ((sigh of relief)) "phew, that's all that's wrong with her" you know…I had grown up with somebody who had hearing loss, you know, don't get me wrong, of course I wanted my baby to be perfect, but you know she is, in another way ((laugh)). And she doesn't have any of the serious complications that were potentially there for her…it was good news for us really, that it was limited to this…it didn't have secondary complications with it (*ITC*, p.241: 2-14).
Rejoicing with Delight	When I did get the diagnosis…it was almost like winning the lottery again. Ya, it was really the best case scenario of what could be wrong. Because at that stage I had accepted there was a loss, so my best case scenario, was that it would be mild, and that would be brilliant news,...So for us, thankfully, we were at the lower end of the spectrum…I remember being absolutely being happy out the day I was told it was mild. I wasn't at all concerned then (*ITC*, p.155: 27-34).

This table captures the array of alternative responses arising from the diagnosis, whereby parents felt disappointed but prepared, hopeful, thankful, and relieved and some even described rejoicing with delight. These positive emotions stand in stark contrast with the previous depiction of parental grief. Importantly, the quotations embedded within the table illustrate that these hopeful responses were typically engendered by one or more specific factors. These determining factors included: having a previous family history of PCHI; valuing early identification; the positive contrast of early versus late intervention; the negation of additional medical complications; and/or receiving a diagnosis that was preferable to the feared prognosis. However, it is crucial to emphasise that these factors do not automatically engender positive responses. For example having an older deaf child with PCHI did not necessarily always soften the grief response, it could augment anguish, particularly if the previous experience was distressing. Likewise, for some parents receiving a mild/moderate, or unilateral hearing loss was still experienced as a major loss.

It is also important to highlight that even with the positivity of these alternative emotions, many of these parents expressed "there were plenty of tears shed" because they desired "the best" for their children, and did not want them to "go through anything unduly necessary" (*ITC,* p.149: 36-39). Subsequently, some parents experienced a blend of emotions from both categories of responses, reporting both grief and hopefulness. This depiction of complex emotional responses was corroborated by the participant check as 100% of parents either agreed (86%) or strongly agreed (14%) that "the explanation of emotional responses in this study are true to my experience" (*PCS,* q.5).

6.3.4 Searching for Information

Regardless of emotional response, parents highlighted the critical need for information during Stage #2. As well as receiving information interpersonally from the clinician, and in a written format from leaflets given to them in appointments, many parents turned to the internet. The extent to which parents relied on this resource was variable. One parent refrained from it entirely explaining "I'm not really an internet person" while in contrast another parent conceded "oh I went online straightaway" (*ITC*, p.170: 35; p.176: 5). Likewise one parent expressed going online only once, while another parent described "looking at the internet every night, ((voice breaks with emotion)) constantly for the first three months ((weeping))" (*ITC*, p.9: 23-24). Thus, the internet-dependency of parents was varied.

The quality of material accessed was also diverse. A number of parents who went online undertook an open internet search. With no filter for quality, and with little understanding of the different levels of hearing loss, many of these parents accessed unreliable sources and poor material, and subsequently got entangled in misinformation or irrelevant information, which caused unnecessary distress, shock, worry, and fear.

> Like my downfall was looking at the internet to see what was the worst case scenario. So I think just stay away from anything like that… [I found] bad stuff….ya you get the worst thing ever (*ITC*, p.52: 1-12).

Parents also described accessing very biased information and articles exhibiting a contentious clash of worldviews which frightened them. Thus, as one parent cautioned, an open internet search can do "more harm than good" (*ITC*, p.171: 22). However, it's important to nuance these negative experiences with the acknowledgement that one parent did discover an Irish-based charity in their online search and proceeded to contact them. This proved to be a tremendously positive experience.

In contrast to an open search, some parents filtered their results. One family (dealing with additional complications) were receptive to the guidance of their paediatrician in this regard and explained:

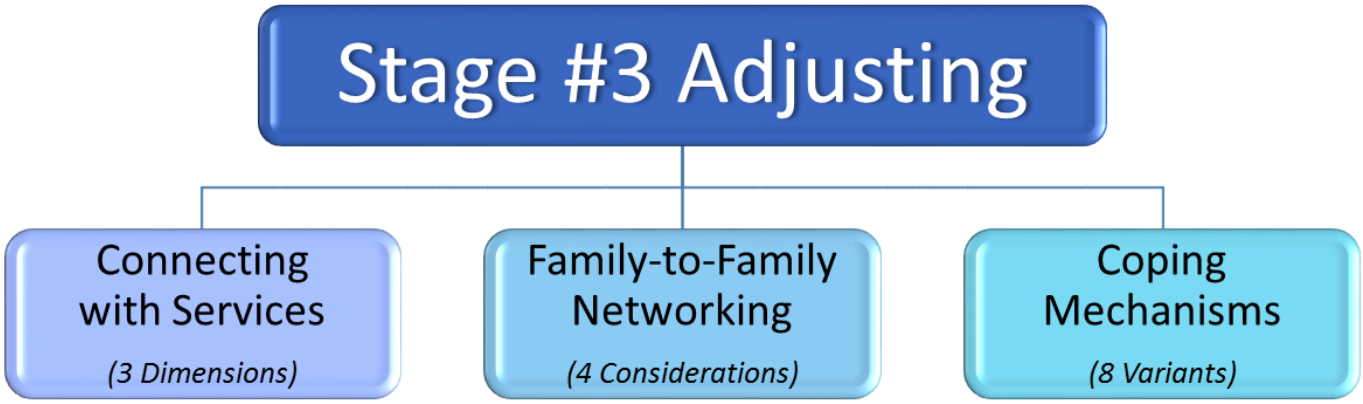
> He took the time to sit down with us on day one, to explain to us what was wrong, and you know, "please don't google it" ((smiling)), so we didn't! And it's true, if you google, you see all the worst things...So he gave us websites that we could look at, to read up and see what her, what it meant for her do you know…he gave us enough information there and then in the hospital to keep us going, but when we came home then, I, did look it up, the websites. We read it once and that was it! We never went back to it again. It was exactly what he told us, there was nothing different (*ITC*, p.239: 34 - p.240: 3).

Another parent expressed only downloading articles from websites that were specifically recommended by HSE literature. Likewise, a different mother described seeking out quality online information such as peer reviewed journal articles, and information from robust sources (her professional background gave her adept researching skills). In these cases the websites consisted of reliable material, which engendered positive and informative results. This safeguarded against poor quality material which was an important protection during the emotional vulnerability of the diagnostic phase. Significantly, this online search was not limited to Stage #2 as the parents' need for information was imperative during every stage of their journey.

6.4 Stage #3: Adjusting

While Stage #2 is characterised by receiving the diagnosis, Stage #3 encompasses the process of adjustment as parents come to terms with their baby's hearing loss in the aftermath of receiving the diagnosis. This adaptation incorporates three dimensions: firstly connecting with the system of services, secondly networking with other families, and thirdly personal coping mechanisms. These simultaneous processes cannot be easily separated as they are deeply intertwined and impact each other. However, for clarity, they will be examined separately. The diagram below provides an overview of the examination to follow.

Figure 6.4 Overview of Stage #3



6.4.1 Connecting with the System of Services

In Stage #3 parents have the opportunity to connect with a wide range of early-intervention services, which can be grouped under the following broad categorisations:

Table 6.4 Breakdown of Services

Category	Services
Clinical Services	• Audiology • Ear Nose Throat specialist (ENT) • Paediatrician • Cochlear implant team in Beaumont (if appropriate) • Speech and language therapy (after 9 months) • Genetic counselling (if desired) • Optometrist
Department of Education Services	• Visiting teacher • Sign language tutor (if desired)
Charity Services	• Social worker specialising in hearing loss (if desired) • Spectrum of family support services (if desired)
Generic Community Health Services	• Family GP • Public health nurse

The coordination of these services, the professional representing them, and the availability of information, impact parental adjustment in Stage #3. These three themes are considered in turn.

a) The Coordination of Services

Parents in the UNHS system identified specific structural features which helped the practical adjustment to the diagnosis. In particular, they drew comfort from being in a coordinated system with a clear care pathway and clinical-led referrals to multi-disciplinary services:

> It's a programme, it really is a programme…it's literally somebody sends out a referral letter to six different professionals, and depending on their departments and how quickly they come back...it's very reassuring that there is a programme, that an administrator somewhere is ticking all the boxes (*ITC*, p.137: 38- p.138: 4).

The timely introduction of these interventions, without long waiting periods, was also crucial:

> The fact that they practically got the hearing aids so quickly, because the horrible time of the diagnosis, am, wasn't that long, simply because a month later we got the hearing aids. And for my husband and I, things totally changed once we got the hearing aids…it was like "great, that's it", you know, the shock is gone, now were doing something about it (*ITC*, p.120: 25-28).

Parents also appreciated when services were sensitive to their specific needs. For example, with regard to the visiting teacher of the deaf service, some families desired regular appointments immediately, while others (following introduction) appreciated being offered time to adjust to the diagnosis. As the myriad of services came into effect parents expressed "we felt like we were always moving ahead, which was great" (*ITC*, p.174: 43- p.175: 1). Thus, a well organised and coordinated system, with timely multi-disciplinary support sensitive to the family's needs was tremendously comforting for parents.

In contrast, parents who experienced the older system of service coordination (prior to UNHS) confronted significant difficulty and distress. They pointed to multiple deficiencies including late-identification, misdiagnosis, no clear system of referrals, no coordinated care-pathway, barriers in accessing services, very long waiting lists, delayed intervention, substandard equipment, lack of time in important appointments, inflexible policies, services acting in isolation from one another, lack of family support and information. After battling to receive a very late diagnosis one parent described:

> We were told it would be 9 to 10 months before the child would be seen to be fitted with hearing aids. That's when, I won't use the language, where I lost the rag.... it had been 13 months almost to the day since I had first raised concerns for the child, and then to be told at [such a late age of diagnosis] to wait 9 or 10 months. But that was it, this wasn't back in the dark ages, this was [a few] years ago (*ITC*, p.146: 24-30).

Rather than supporting parents as they adjusted to the diagnosis, this older system augmented their distress. Parents lost a sense of trust in the system as "they had to fight every step of the way", strenuously advocating for basic services (*ITC*, p.137: 29-30). Importantly, these parents were careful to highlight professionals within the system who did help them combat many of these structural difficulties. However, as one parent expressed, gaining access to these proficient professionals was often a struggle:

> There was also a lot of, I suppose, you could almost call it sweat and tears to get what ultimately was there, the services were there, and once you had access to them the individuals involved were absolutely better than good. They were absolutely excellent, but it was to get your foot in the door (*ITC*, p.147: 28-31).

Thus, parents reported that many excellent professionals operated within a flawed structure of services.

It was clear from the research that the manner in which the services are organised yields a tremendous influence in the parent's adjustment. The previous poorly coordinated system of services caused ample distress, frustration, and anguish to families. The amended coordination of services engendered tremendous comfort, relief, and thankfulness. In contrasting the old and new systems one parent stressed "I mean there's NO comparison like, no comparison" and another emphasised "it is just so far improved" (*ITC*, p.137:26; p.17: 21). However, the amended system is still in formation, and many parents highlighted the need for improvements which are outlined in Stage #4. Nevertheless, it was predominately depicted as positive in its capacity to support families as they adjust to the needs of their newly diagnosed baby.

b) Engaging with Professionals

As well as the coordination of services, the individual professionals embodying these services had a tremendous impact on parental adjustment. It was clear from the research that many parents often built a very significant relationship with one or two core professionals in particular who became central, trusted figures for the family. This interaction was instrumental in supporting parental adjustment. Different parents gravitated towards different professionals, and many built important relationships with their audiologist, visiting teacher, speech and language therapist, cochlear implant team, charity, paediatrician, and sign language tutor. Parents valued the following characteristics in these professionals:

Table 6.5 Characteristics Parents Value in Professionals

Characteristic	Quotation
Good Rapport with Parent	We were very lucky as well that, I suppose, we made a good connection with the [professional] ...She was very supportive (*ITC*, p.16: 36-37).
Professional Expertise	So straight away she knew exactly what was going on. [She was] fantastic. Absolutely fantastic. The difference was tremendous. She knew exactly what to do. She knew exactly what to tell us (*ITC*, p.19: 33-36).
Accessible & Available	She's always on the end of a phone if we need her (*ITC*, p.187: 38).
Empathetic & Supportive	[The professionals] were fantastic, am, I felt they were very supportive and they were very empathetic...I felt like we were looking to them for everything (*ITC*, p.187: 34-36).
Celebrating the Baby	And she just said to me, ((in soothing, soft, reassuring tone)) "she's a gorgeous little baby, just enjoy her. She's just normal" (*ITC*, p.30: 36-38).
Personable, Warm, Compassionate, Reassuring	He is a real sweetheart like…you know the way some of them would be stiff and starchy like, but sitting down and he'd [say]…((reassuring tone)) "don't be worried about her now, she's fine, we'll check it all out and she'll be grand. Look at her, isn't she gorgeous, look at those blue eyes, look at them", he was all this which was lovely like, do you now. Real like ((reassuring tone)) "Don't worry about it'll be fine. We'll sort everything out, we'll get it all checked out, if she needs anything we'll do that for her too" you know. Ya, it was lovely...he called in every day to see how she was doing, it was really, he is a lovely, lovely guy, you know. And even when we go up [now], he'd be saying ((affirmative tone)) "don't worry about her anyway, she's fine look at her" ((laugh)) (*ITC*, p.240: 7-17).
Strong Rapport with Baby	[My baby boy] knows the department so well, we go to the…door and he's all excited because he just loved [the professionals]… so it was great … he knew the people there and he knew the department, we really felt he mattered (*ITC*, p.179: 16-20).
Child-Centred Practice	Some of them are fabulous, like he loves going to [one service in particular]…and they actually know him. They know that he doesn't like the dark, so they don't turn off all the lights, they leave some of the lights on…like its brilliant going, going out there they know his name, like every time we go out there they say you know he is after growing… and he likes it there…he's a kid, that would actually be insulted if you put him in a high chair, so they kind of put him on a seat and pin the table into him, they won't put him in the high chair anymore, and he likes that like, he prefers just sitting on the seat. So it's nice going to a place that know him, they can have it all set up, the room all set up for him...they are very good that way (*ITC*, p.52: 19- p.53: 4).
Excellent Explanations	They kind of explain too in…straight talk or the easy talk…they kind of gave you a different understanding....And that was brilliant (*ITC*, p.226: 14-16).
Giving Time, Hope, and Direction	He spent an hour and a half on the phone with me. And am. I suppose he calmed me down. He told me it wasn't the worst thing in the world. He told me what the possibilities were and more importantly he pointed me in the right direction. So he said you basically need to do the following things very quickly…And I followed that advice and we got [the services and supports we needed] (*ITC*, p.16: 17-20).
Commitment	I think with us, like [our professional] goes over and above her job. Absolutely… She's very, very good (*ITC*, p.44: 1).

The significance of the characteristics listed in the above table should not be underestimated. Parents emphasised their immense appreciation for professionals who generated a rapport with the family, celebrated the baby, engaged with professional expertise, adopted a child-centred practice, provided excellent explanations, offered ample time, hope, and direction, and were generally accessible, available, empathetic, supportive, personable, warm, compassionate, reassuring, and committed. Parents highlighted that the professionals who embodied these characteristics were "phenomenal" (*ITC*, p.44: 26). The rare occasions where parents encountered the opposite traits in professionals (e.g. lack of rapport, expertise, time, etc.) resulted in parental distress or discouragement. Therefore these characteristics, either in their presence or absence, were seminal in shaping the parent's relationship with the professional, and as a consequence, their experience at large of the services.

c) Seeking Information

One of the biggest requirements parents experience in Stage #3 is the need for good information. The categories of information parents require at this point can be classified as:

- **Clinical information** explaining the child's specific diagnosis and intervention options
- **Communication information** outlining the spectrum of communication options as well as advice for how to interact with a deaf new-born baby
- **Technical information** educating parents how to manage technology
- **Care-pathway information** to inform parents of the key services available to them and the subsequent referral process (with all the applicable contact information provided)

- **Signposting information** highlighting the wider supports and organisations available to the family in the community (including charities) with up to date contact information
- **Fiscal information** regarding the social welfare and tax benefits available to families
- **Parent-led information** arising from other families' stories, insight, and advice
- **Educational information** listing websites, organisations or literature for further information

Parents accessed multiple sources in seeking this breadth of information. They described gleaning knowledge from consultations with professionals, information leaflets, charity information nights, charity weekends away, networking with other families, chance meetings with parents in waiting rooms, correspondence courses, the internet, and even manuals for professionals. Three parents emphasised that because the breadth of information was not collated into one source, the information parents receive can lack a sense of coherence. Thus, parents indicated that the acquisition of knowledge often lacked a sense of structure, and reported that it was accumulated in a very "hap-hazard and random" capacity over chance conversations (*ITC*, p.31: 36).

One parent in particular emphasised that this lack of structure is reinforced by different professionals giving parents different leaflets in different appointments. She expressed "I've a collection of leaflets, but there is no order to them like" (*ITC*, p.170: 19-20). She stressed "they end up…in the handbag, the changing bag, kitchen table, work top, put into a file, with the post" with no sense of coherence (*ITC*, p.170: 12-13). She strongly recommended collating the information into something akin to the "pregnancy pack" which mothers receive in antenatal appointments

> The more and more I think about it, there is a pack required. There is a little information pack required… make it a pack, make it a reference (*ITC*, p.168: 27-36).

This recommendation resonated with the desire of many parents for information in a written format, explaining that they prefer to sit down and read a hard copy, referring to it as needed. Significantly, two of the parents had actively addressed this problem by participating in a group (run by a charity) to design a pamphlet for parents of newly diagnosed children, collating the information in a succinct format. However, the consistent dissemination of this leaflet across Ireland (and other booklets created by charities to collate information) seemed to be lacking as other parents in the sample did not indicate receiving it. This is an important issue because parents consistently correlated the acquisition of knowledge with a sense of empowerment.

6.4.2 Family-to-Family Networking

One of the strongest desires parents habitually described, upon receiving an early diagnosis, was to connect with other families who had been through the UNHS system in Ireland. One mother articulated "all I wanted to do then was meet kids with hearing aids" (*ITC*, p.105: 21-22). The following four themes arose during the course of data analysis.

a) Missing Connections

Within the participant check, parents were asked to rank the statement that "connecting with other families is beneficial for coping with the hearing loss diagnosis" (*PCS*, q.8). Eighty-three percent of parents who responded on the Likert scale expressed their strong agreement[25] (*PCS*, q.8). Importantly, this statistic does not include the response of one parent who refrained

[25] The remaining 17% of parents indicated that they neither agreed not disagreed with the statement (*PCS*, q.8). These statistics were generated on the basis of the 6 parents who indicated their response on the Likert scale. One parent refrained and gave a written response to this question, which is not included in the statistic but is detailed above.

from answering this particular question within the Likert scale, but instead explained that they had "no opportunity to meet with other families to-date" (*PCS, c.1*). This participant expressed that "we would have liked the chance to meet with other parents who experienced [a] similar diagnosis" (*PCS, c.2*). This unmet desire was also articulated during the interviews process. As one parent described:

> You do feel like you are operating in a bubble, because I don't know anybody of [my baby's] age, who has hearing impairment…that are dealing with the system right now. Do you know? That there is no network… there is no support…if you just had a concern, or you know, a query, or just to chat to somebody else who knows where you are coming from… Say that time now when I couldn't get a [specific] appointment for [my baby], I had no other parents that I could say "look are you having the same problem? Is it just me?" do you know? Or like, is there, can we as a group get this moved on anywhere you know (*ITC*, p.243: 3-12).

Another parent in the same predicament humorously described that she "was almost trying to stalk the waiting room" of her appointments, desperately hoping to bump into families in the same situation (*ITC*, p.140: 25). These parents strongly recommended facilitating these connections as a means of improving the system.

b) Parent-to-Parent Networks

Participants who engaged in parent-to-parent networking (in person or online) emphasised its positive impact. These interactions were infused with empathy, understanding, and reassurance. They dissipated a sense of isolation, soothed anxiety, fear, and worry. As one participant explained:

> [The other parents] understand where you are coming from, do you know? I suppose it's very hard to get inside the head of somebody and the experience they are going through if you haven't gone through it yourself. Whereas other people we would meet in [the same situation] …I suppose they understand, where you are coming from in terms of your emotions and your loss, and your devastation and all that. So I suppose that's the difference (*ITC*, p.217: 11-16).

As well as providing emotional support, these networks also provided a forum for information sharing, thereby empowering parents to gain knowledge and overcome challenges.

> Since his diagnosis, we've met more parents with babies…there was one lady…and she gave me a lot of help about keeping hearing aids in, she'd been through it with her boy. There is more babies coming on stream and we kind of feel we can empathise with them, and it's just nice to feel you can maybe help other people as well because it's such a steep learning curve, you know? (*ITC*, p.187: 3-10).

These connections also nurtured a sense of solidarity. Parent's accessed a community of support as they shared their journey with one another in an ongoing capacity

> It helps to share the stories…like you are able to follow their story as well, and it's really encouraging to see you know a child whose been switched on a year and they are starting to say sentences or whatever and it's like "ya, we can get there too, we can work at it and go at it together". So ya, it really helps (*ITC*, p.187: 10-26).

These networks also nurtured solidarity in advocacy as parents jointly tackled problems they encountered in the system. Thus, the benefits of parent-to-parent connections are manifold. As one parent stressed "you get more out of that than anything else" (*ITC*, p.38: 5-8).

Parents connected with one another in a host of creative capacities, including one-to-one meetings, telephone conversations, parents' events run by charities, chance encounters in waiting rooms, and/or specific social media sites (such as a Facebook page for parents of deaf children in Ireland). The latter was particularly useful for parents who lived in a geographically remote area without easy access to parents' events. Whatever the mode of connection, parental reports suggest that parent-to-parent networking was immensely significant.

c) Deaf Role Models

A positive encounter with a Deaf role model was a transforming experience for many parents. One couple experienced meeting an older Deaf child at a parents' information session

> Then they brought in a 10 year old, it was actually the best experience I think we ever had, because she was profoundly deaf at birth, was diagnosed at I don't know, 2 or something, was implanted, and then she was incredible, absolutely incredible. She had a Dublin accent, was sitting chatting away to us, answering questions, and we just looked at each other and said ya there's nothing to worry about here, it's absolutely fine…[we] just got the feeling, this is completely normal you know (*ITC*, p.183: 7-17).

These interactions precipitated a dramatic transformation in parents' perceptions. Rather than seeing deafness as debilitating or marginalising, they now saw all the possibilities and potential open to their baby. It also engendered a profound sense of reassurance, relief, peace of mind, and normalised the situation for parents. Parents also described being infused with a new hopefulness and empowered with a positive perspective. As one family expressed "that was the turning point, saying, there is hope, we can do this" (*ITC*, p.42: 18-19). Parents drew similar encouragement when encountering Deaf adults, adept in communication and succeeding in life.

Although the majority of parents drew comfort from meeting a Deaf role model who communicated orally, two families were inspired by their encounter with a Deaf lady who communicated entirely with sign. The success of the lady's life, her humour, her capacity to live in both the Deaf and hearing world, and the friendship that grew between them was very significant in moulding these families' perceptions of how a Deaf-signing adult can thrive. One parent described

> She is an amazing person, she would certainly would be able to lip read a little bit, and she has sign language… [She is a] lovely person and…has obviously got through life really well, and she is an inspiration to anyone that may have a child that is profoundly deaf (*ITC*, p.162: 2-5).

However, this reaction was not universal[26]. Another parent felt a barrier when encountering a Deaf adult who signed because she couldn't communicate with her and struggled to feel a sense of connection. Also, the introduction to the world of hearing loss (be it sign or speech) could

[26] Regardless of what role models parents were drawn to, the majority of families in this sample (who discussed their communication choices) were engaging in both modes of communication, with the perspective of giving their child the best of both the hearing and Deaf world.

initially be overwhelming for families. One parent felt a sense of shock when seeing a group of children with hearing-aids and cochlear implants for the first time as the reality of their baby's hearing loss suddenly became tangible. Thus, there was a complex mix of feelings for parents as they encountered diverse role models from a spectrum of life stages.

d) Recommended Cautions

Although family-to-family networking was predominately positive, the following seven cautions were recommended in interviews. Firstly, the mentoring parent should be further along the process and able to give retrospective reassurance and advice.

> I don't know how helpful it would be for two people at the same time of diagnosis to be together, because then you are just both upset together…[whereas] you might hear a parent of a slightly older child say, "oh its great she knows like, she walks to the door when I say door". And you're like ((enthusiastic tone)) "what!! She does!!!"… You are desperate to pick up on any of those kind of little things (*ITC*, p.140: 32- p.141: 8).

Secondly, a mentoring parent should have a positive experience of the UNHS system in Ireland.

> I've spoken to people that their kids were diagnosed before the [UNHS] programme, like older ages and stuff. And I mean there's NO comparison like, no comparison. And that's why it's not really helpful talking to them, because we're all fairly positive…just so thankful for everything, and you know, but the people before…had to fight every step of the way, you know, to get a diagnosis…They are just very different outlook and they don't necessarily know that things are so good for us (*ITC*, p.137: 25-31).

Thirdly, a mentoring parent should be grounded, hopeful, and positive.

> You know, pick your parent too, I don't know, you kind of know in advance who will be hysterical about the whole thing (*ITC*, p.141:42 – p.141:1).

Fourthly, there should be a balance between giving reassurance and listening to feelings of loss.

> So I suppose if I meet parents [of newly diagnosed children]…on the phone I'd talk to them, do you know you'd answer their questions. I'd be reassuring at the start, but then I'd let them have their give out, and moan as well, because I suppose, they're feeling hard done by, and cross and whatever (*ITC*, p116: 33-36).

Fifthly, families with a similar (not different) diagnosis should be linked with one another.

> For somebody whose told that their child is profoundly deaf, to put them in contact with someone whose child has a mild hearing loss would be almost be an insult I think. It would be almost hurtful (*ITC*, p.161: 32-34).

Sixthly, parents who experience a dual-diagnosis require special care and exposing them to families or children with just a hearing loss could be very hurtful.

> They were having a meeting one night for new parents so we went to that, and it was probably a mistake for us to go to that, it wasn't suitable for us to go to that <u>at all</u>. It was all children who had, hearing loss, nobody else had the additional [needs] …and all of them had very positive stories … [but] they didn't have the extra [complications]. So that wasn't a good idea to go there at all (*ITC*, p. 216: 17-29).

Finally, while a positive perspective can be very hopeful, if it is not applicable to the circumstance at hand, or if it is given to a parent who is struggling to cope, it can leave the parent feeling "burnt" (*ITC*, p. 93: 7).

These seven cautions are important given the emotional vulnerability of parents during Stage #3. However, the parents who articulated these cautions, did not discard family-to-family networking. On the contrary they emphasised the critical need for it, advising that it should be facilitated more consistently, albeit with care and consideration. Accordingly, within the participant check 100% of parents either agreed (71%) or strongly agreed (29%) that "hearing loss professionals should facilitate family to family connections" (*PCS*, q.9). This endorsement represented one of their key recommendations for improving the UNHS system.

6.4.3 Coping Mechanisms

As well as connecting to a system of services and networking with other families, Stage #3 also encompasses the internal struggle to process grief. Eight distinct coping mechanisms were identified as participants described the personal process of adjusting and coming to terms with the diagnosis. Interestingly, a number of the coping mechanisms are either precipitated

by, or deeply influenced by, encounters with other families, professionals, and services. Each of these mechanisms for coping with grief are outlined below.

a) Restraining

Particularly in the immediate aftermath of the diagnosis, some parents felt that the grief was too raw and painful to express to wider circles of people in their lives.

> Oh it was dreadful. We couldn't tell people at that stage because we just couldn't.... It was just absolutely dreadful. I was nearly ready to burst into tears the whole time. Absolutely dreadful (*ITC*, p.30: 18-22).

This response was generally an early reaction to the diagnosis as parents were struggling to process the news themselves and not yet ready to break it to others.

b) Withdrawing

Some parents described the experience of being so overwhelmed by grief that they withdrew socially for a time

> I ((voice breaking with emotion)) don't want to see anybody on the first three months ((weeping)), my friends like ((weeping))…so I used up a half years' time to build up my confidence ((weeping)) and to face the real world ((inhale while weeping)) (*ITC*, p.4: 18-21).

Another parent explained that this withdrawal is a response of "mourning" (*ITC*, p.34: 16).

c) Releasing

Upon receiving the diagnosis, many participants expressed "I remember I was upset" (*ITC*, p.34: 27). Parents described releasing their grief through talking and tears. The outpouring of grief was sometimes involuntary, as parents described being unable to restrain their emotions:

> Like every time we go to see any kind of doctor ((weeping and inhale)) I can't control my emotions (*ITC*, p.5: 6-7).

The release of emotion seemed be an important outlet, particularly when expressed to an empathetic listener (be it a professional, parent, or family/friends) who responded with compassion. In addition, participants also strongly emphasised the importance of "talking to parents. To me that's the key. Talk to other parents" (*ITC*, p.41: 23-24).

d) Denying

As well as an emotional response, denying or disproving the diagnosis is also a coping mechanism. One professional explained that "the mind will always find evidence" to fuel this misgiving (*ITC*, p.90: 22-23).

> But if you've often got an intelligent child…they are quite responsive visually, and…the deaf baby will gurgle like the hearing baby, so it looks like they are gurgling...So [the parents] would be looking for evidence of hearing. There would be, I think, initial denial (*ITC*, p.86: 2-6).

Participant reports suggested that for the majority of parents this denial was a passing response, rather than an enduring rejection of the diagnosis (in this study it appeared that the latter is possible, albeit rare).

e) Seeking Solidarity

A number of parents appeared to cope by seeking solidarity. In connecting with other parents in similar situations, they described finding empathy and reassurance which they emphasised was immensely powerful.

> You think you are the only person that has a child with a hearing loss until you get into the circle, you discover there is an awful lot of them ((smiling)). You don't realise how many there are…They are in the same situation like (*ITC*, p.167: 40 – p.168: 2).

Parents also explained that they found solidarity from empathetic and supportive professionals who walked through the journey with them. Significantly, the data indicated that this solidarity dissolved the isolating sense of being alone.

f) Redefining Encounters

A significant turning point for many parents was their redefinition of deafness. The experience of meeting a Deaf child was particularly transformative, refashioning parents understanding of hearing loss, and redefining their perception of their child's potential. One professional emphasised that:

> I think it is really good for [parents] to see Deaf kids succeeding, and Deaf adults succeeding and just [realising] ya Deaf is normal. Deaf only stops you hearing some things, but it doesn't stop you doing anything else (*ITC*, p.79: 18-19).

As one family expressed "that was the turning point [for us], saying, there is hope, we can do this" (*ITC*, p.42: 2-7). This hopefulness engendered a new sense of positivity and potential.

g) Rationalising

Parents also coped by employing their adept reasoning skills and rationalising though their perspective of hearing loss.

> The way we looked at it was, we could sort of say "oh God we have a deaf child that's awful" and let it take over your whole life…but there's no point doing that, you are not giving anyone any benefits from that (*ITC*, p.185: 29-31).

Parents explained,

> We kind of rationalised it a lot I suppose, and decided that this is going to be something positive. The obvious response we were getting from people is "this is terrible", but, actually, is it, you know? It wasn't that bad ((laugh)) you know, once we kind of got our heads around it (*ITC*, p.177: 28-31).

This rational approach was influenced by the parent's research on the subject, which fashioned a grounded hopefulness. This perspective dissipated much of the force of the grief.

h) Proactivity

The majority of parents in this sample eventually (or quickly) adopted this task-centred coping mechanism. Having worked through many of the previous responses, they described pouring their energy into proactively enabling their child to reach their potential.

> I think coming to terms with anything if you feel there is something you can do to help it, it really helps in the coping process…you feel there's a way forward here and there is a way of improving things then you just focus on that and you go with it. We found that's been really helpful…because we know [our baby] should be capable of whatever we wants to do if he has the right back up, so we want to try and maximise his chances, and whatever he decides to do in life is fine...but it's certainly a coping mechanism to deal with that (*ITC*, p.185: 9-21).

Many of these parents were actively engaging in both speech and sign, with the perspective of giving their child every tool and opportunity. This task-centred approach was experienced as very empowering and positive, particularly as parents saw their children making progress. Some parents depicted this proactivity as a means of overshadowing grief rather than being consumed by it, while others explained that it arose from having confronted their grief and moved on. Either way, their grief was largely eclipsed (but not entirely dispelled) by a very proactive mind-set that was pragmatic, forward-looking, and task-centred.

The Impact of Relationships

Parents' experiences of these eight responses can be deeply affected by close interpersonal relationships. Two parents within a family can react with conflicting coping mechanisms. For example if one parent responds proactively, while another falls into denial, these conflicting responses can be a tremendous source of tension and pain during Stage #3 and beyond. The reverse is also true, whereby two parents can work through these coping mechanisms together, supporting and caring for each other during acute vulnerability. These dynamics are explored in more detail in section 6.5.4.

Likewise, the extended family can be a vital source of emotional and practical support to the parents in the aftermath of the diagnosis. A professional highlighted that one particular child's "extended family went off and learned sign language", she explained that "you know that child is going to do great, she's got her whole family behind her rooting for her (*ITC*, p.80: 8-10). However, in other circumstances extended family, friends, and acquaintances can also precipitate strain and stress. Some parents needed to repeatedly explain the diagnosis, emphasise the hopeful interventions, dispel misconceptions, and constantly provide emotional reinforcement. As one parent expressed "I mean I was blue in the face from trying to go through the happy thing. And that was a bit difficult in a way as well" (*ITC*, p.190: 5-6).

Reflection on Coping Mechanisms

These coping mechanisms are not prescriptive. They do not occur in a set order. Every variation was not experienced by every parent and many parents adopted a number of them simultaneously. The trustworthiness of these coping mechanisms was tested within the participant check. In response to the statement "I experienced at least one of the coping mechanisms explained in the presentation" 100% of parents indicated that they either agreed (43%) or strongly agreed (57%), which substantiated the eight classifications (*PCS*, q.7).

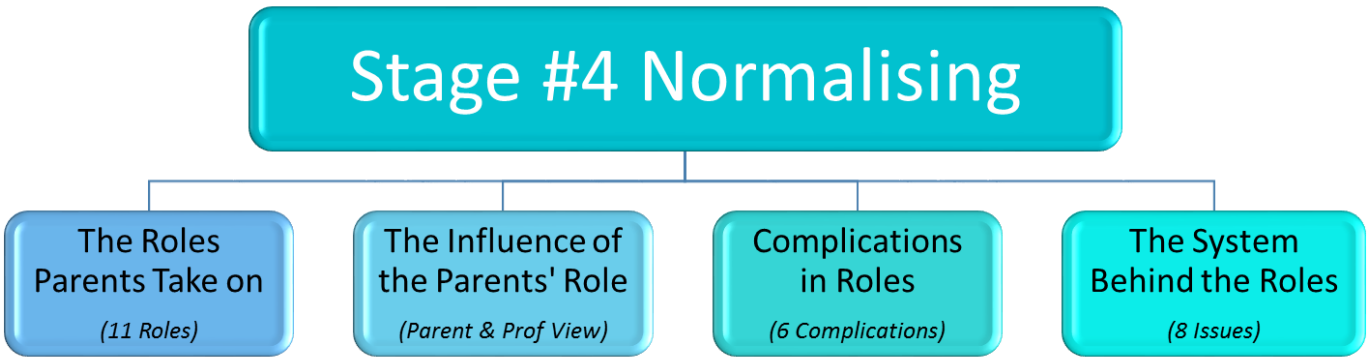
6.5 Stage #4: Normalising

Stage # 4 encapsulates the return to everyday life. As one professional articulated

> I think at that stage families have come a long way, enough time has passed that …for the most part there is a lot of acceptance around hearing at that stage, they've seen their baby continue to develop in, possibly, a typical way…they realised…there hasn't been too much negative impact on the child's development, in the case of straight forward hearing problems, and they are managing hearing aids well, they have had access to services. They understand the process, they've built relationships within the team, and they are on their journey and it has become part of their everyday life really. Dealing with a child with hearing problems (*ITC*, p.210: 1–9).

In a minority of cases, where the child had a particularly complex or dual diagnosis, parents are dealing with ongoing uncertainty and working through alternative interventions and decisions. However, whether dealing with certainty or uncertainty, Stage #4 is characterised by the four subcategories (as illustrated below) each of which will be examined in turn.

Figure 6.5 Overview of Stage #4



6.5.1 The Roles Parents Take On

By Stage #4 parents described undertaking an abundance of roles and responsibilities to cater for their child's specific needs. These roles often become integrated into everyday life to the extent that they become "second nature" to the parent (*ITC*, p.106: 6–10). The roles that parents assume can be classified under the following eleven categorisations.

a) Actively Engaging with Services

Parents in this sample habitually placed a tremendous value in actively engaging with services. As one parent expressed, "it didn't matter what time of the day they told me to come back with the baby that was the utmost thing that needed to be done (*ITC*, p.149: 42–43) These parents regarded appointments as an absolute priority, regardless of the time, travel, effort, or inconvenience it incurred. Furthermore, many parents articulated that their engagement encompassed much more than passively attending appointments with a baby:

> Every appointment now I go to, it's never kind of a routine appointment you sit there and, and go, you know. There's always things to ask or to change or to, you know, you kind of need to make the most of every appointment I think (*ITC*, p.126: 33–36).

In particular, parents made "the most of every appointment" by preparing in advance (*ITC*, p.126: 33–36). This preparation encompassed writing out questions to ask, bringing reports and administration, giving updates on the baby's development, raising concerns, and highlighting areas they wanted to understand better. Consequently, appointments were seen in a positive light, as opportunities to gain clarity, information and fine tune intervention.

b) Ongoing Learning

Parents described that there is initially a "steep learning curve" as they struggle to understand the manifold components of hearing loss (*ITC*, p.187: 12). During Stage #3 and #4 parents continued to diligently seek out and learn as much as they could on the subject:

> [She] gave me a lot of literature the next time, and I remember going bananas then downloading things from all over the place from am the NCDS in the UK, oh <u>loads</u>, and I remember…the visiting teacher came <u>really soon</u> after then which was great…she told me about this Elizabeth Foundation in the UK…they send you correspondence kind of. I mean I was straight on (*ITC*, p.124: 33–38).

Parents diligently engaged in "researching" and explained that "I read everything I could get on hearing loss" (*ITC*, p.176: 11–16). As a consequence, many parents developed a sophisticated knowledge, and adept capacity to read audiograms and understand the intricacies of their child's diagnosis/intervention. They sought not only to gain academic knowledge, but to apply their learning, with the mind-set "tell me what's important, we'll do [it]" (*ITC*, p.24: 16). This level of comprehension and application was tremendously empowering, enabling parents to take on their roles and responsibilities with great skill and confidence. It also enabled them to interact with professionals in a collaborative capacity, and have a significant input in fine-tuning intervention. Importantly, the imperative to learn remained an ongoing and continuous requisite for parents, particularly as they encountered new milestones and challenges.

c) Reinforcing Communication

Parents have a critical role in reinforcing communication interventions. Many professions (particularly the visiting teacher and the speech and language therapist) operate by teaching parents specific communication skills, which the parent subsequently reinforces with their baby.

> Obviously the parents are the best teachers, [and] are ultimately the person who is going to be caring for the child…So the idea is if [the professionals] can give the [communication] skills to the parents, then the parents can use the most opportune time to implement those skills. Personally I think it's a <u>real</u> step forward…to be able to equip the people who are ultimately with the children, with the necessary skills. Now, not, of course, it needs to be followed up still with the weekly or the bi-weekly or whatever meetings with the [professional] to make sure, for the parent's sake even, that what they are doing is on the right track (*ITC*, p.148: 23–33).

Participants described how essential it was to integrate these skills into everyday life in a concentrated and consistent capacity. As another parent emphasised:

> it has to become part of your routine… it is about spending the time because you find sometimes, if you're particularly busy…and you miss a few days, you really see he hasn't progressed, whereas it is very, very important to have the one-on-one reinforcement of words all the time. Because they just don't learn by the picking up of noise, they have to be sort of taught every word, am, so, its ya, it's just making it part of the routine and making sure you don't miss out on it (*ITC*, p.191: 37 – p.192: 11).

Thus the parent is the instrument of intervention, with the perspective that "everything is an opportunity" for language stimulation (*ITC*, p.191: 18).

d) Managing Technology:

The parent has a key role in managing the baby's assistive hearing technology, be it hearing aids or a cochlear implant. Initially this was a daunting task for parents, many of whom described feeling overwhelmed and fearful:

> You go up and you get your hearing aids. God I remember being…terrified of them, because you were not used to anything like that. And I suppose [my baby] was so tiny at the time, fitting them on her ears. But now, its second nature do you know what I mean. I think once you had 2 or 3 weeks at home doing them, you didn't take any notice. And you were showing your family how to do it then, do you know, you got very confident from doing it every day (*ITC*, p.106: 6–10).

As well as becoming very competent, confident, and relaxed in managing assistive technology over time, parents also described become adept at judging when hearing aids are getting too small, how to prevent damage if it gets wet, and how to identify faulty mechanisms.

e) Ensuring Use

As well as managing the technology, the parent has a related and crucial role in ensuring they are worn. This was a particularly difficult task at the toddler stage, one parent described:

> Lord like, you know she really wouldn't leave [the hearing aids] in at all like. And they get so good at hooking them, and she managed to even take them apart…you know they get their little fingers into the little tubing and manage to pull it out, am, I mean the same way she'd be pulling off her socks and stuff, it wasn't particularly those. So that lasted from about 5 months to 16 months… [taking them out] like chewing them and sucking on them and throwing them (*ITC*, p.123: 12–32).

A number of parents emphasised that the daily struggle of trying to keep hearing aids on the toddler was a "nightmare" and expressed "you couldn't leave him in a room by himself for a minute because he'd be at them". (*ITC*, p.181: 38–43). Critically, parents in this sample persisted, taking their role of *ensuring use* very seriously and sought out creative solutions (such as hearing halos) which made a tremendous difference. Many parents described that once the baby was old enough to feel the benefit of the assistive technology, their attitude changed completely and they began looking for their hearing aid/cochlear implant in the morning, and pushing it back in when they were falling out. However, the persistence of the parents prior to this turning point was one of the most challenging roles they struggled with.

f) Monitoring

Parents have an important role in monitoring the baby's development, and relaying their observations to professionals, thereby influencing in the fine tuning of intervention. One parent explained:

> there is so much that am, a parent picks up that the am professionals act on you know… you come in and they say, "so how has she been"… But from what you say they start writing it down and going ok, "she's not saying that yet, maybe she's not hearing that sound", and you know little throwaway comments of *parents* observations can kind of, really am impact how they tune the hearing aids (*ITC*, p.126: 10-15).

Consequently, some parents carefully monitored their baby's progress and milestones, keeping notes of their observations, in order to accurately relay the baby's development at various appointments. Parents who described taking on this role emphasised that the professionals they encountered listened to them respectfully and took their insights seriously.

g) Networking

A number of families were particularly active in networking with other families. By engaging with charities, or online forums, they had many opportunities to connect with other families and link into an ongoing network of support.

> I think the parent to parent conversations, you get more out of that than anything else... it's the whole reassurance and support is, you need the other parents there for that. Absolutely. And also you hear the tip that, because I remember, we went to a few different kind of nights or days or whatever. And it was through one of the parents talking … she was telling us little things to watch out for [and do]…and so that's why we've done that. I don't know whether we'd [have thought of that ourselves], you know, its little things like that that make a huge difference for us and for [our child] (*ITC*, p.38: 5–16).

This parent-to-parent engagement was crucial in providing emotional support, information sharing, advice, and a sense of solidarity in sharing the journey. Having benefited personally, these parents actively sought to give support to families of newly diagnosed children, and strongly expressed in interviews "if I can be of any help to anyone, I'd be only too happy to say what our experiences were" (*ITC*, p.167: 8).

h) Administration

The parent often takes on the role of an administrator, filing all audiograms, reports, letters, and documents in a folder for their child. This was particularly important and useful as parents came to make applications (and re-applications) for benefits such as domiciliary care allowance. However, there was a second reason for this administrative role, namely to compensate for weaknesses in the wider health care administration itself. Many parents observed that information and reports were often not circulated between different services in the community and health-service, despite the indications to the contrary. This was particularly problematic in complex cases, particularly if one professional needed the input of another.

> The only problem we did have was getting reports, ya every time we went for the follow up visit the reports had never got there. That was frustrating alright. So what I started doing then, was I took a copy on the day ((laugh)) and brought it with me myself to [the next] clinic (*ITC*, p.236: 17–19).

Thus, a number of parents described having to assume this administrative role upon themselves, relaying information from one professional to another in providing reports and verbal explanations.

Furthermore, a number of parents confronted confusion in the administrative protocols of the health-care system itself. For example, one parent explained the predicament of moving from one clinic to another within the same discipline. When she never received an appointment with the new clinic, she took the initiative to resolve the oversight and discovered that the services had not exchanged information with each other supposedly due to confidentiality. It took the parents initiative to contact both services a total of five times, identify this impasse, give the consent they needed but had never requested, and initiate not only the sharing of information between services, but also the follow up appointment. In reflecting on this administrative confusion, the parent expressed "that's a bit daft" (*ITC*, p.237: 21).

i) Mediating

As the parent took on the above administrative role, they effectively began mediating information from one service to another. Particularly due to the absence of direct multi-disciplinary interaction and consistent sharing of information, the parent became a link worker, striving to bring a sense of continuity to their child's care.[27] As one parent expressed:

[27] This role was sometimes undertaken by some dedicated professionals who sought to address this problem by linking with other services and either seeking or sharing information. However, in Stage #4, this seemed to rest on the initiative of the individual rather than representing a formal protocol.

> There is no one who oversees the whole programme, the overall how the child is doing, so I suppose, that's the role that the parent might take on you now (*ITC*, p.143: 3–5).

Not only did parents describe mediating information between different services, but they also undertook this role within one service if there was either a rotation of professionals, or long gaps between appointments. Parents highlighted that in these predicaments, the professionals' lack of familiarity with the family was enhanced by the practice of not reading their notes in advance (to know the details of the previous appointment), and also not having up-to-date multidisciplinary reports in their file (to know the up-to-date details of the child's diagnosis):

> I think it's very important too for staff… to read the file before the parent comes in. like we've had people calling our child °the wrong name° ((sad laugh)). Or asking you the same questions that they asked the previous time, and they asked the previous time like (*ITC*, p.220: 2–6).

Some parents countered these problems by not only providing recent reports, but also by documenting the details of previous appointments to relay this information at the present appointment. Thus, in their role as a link worker the parent strove to not only bring continuity between services, but also within services.

j) Advocating

Advocacy was a strong theme that reverberated in many interviews. One parent explained:

> I'm not one of these pushy mums at all ((laugh)), I don't think, but I think when you see a problem especially when it's your child, you'll do whatever you have to (*ITC*, p.191: 24-25).

On an individual level parents advocated for appointments (combatting delays, or being overlooked), for specific services (that were difficult to access), for new equipment (as they experienced technical problems), and raised concerns regarding their child's development. They were motivated by the desire to remove compromises to the baby's care, explaining "if

you don't do it, and you don't speak up for them, then who else is going to do that?" (*ITC*, p.228: 23–25).

A number of parents highlighted that they experienced the support of professionals who listened and responded to their advocacy in a respectful manner. One parent explained:

> I kind of advocate on [my baby's] behalf because a lot of things wouldn't have happened if, you know even lately, I went in and said, ((explaining tone)) "you know the hearing aids every now and again they turn themselves off, I don't know why"…straight away they said, ((no problem tone)) "fine, here's another pair"…which is lovely that you have that level of trust (*ITC*, p.126: 36–42).

Furthermore, parent's also stressed the commitment of supportive professionals who often advocated on their behalf when it appeared that their voice was having no impact.

On a corporate and political level, parents advocated for changes in government policies. Parents advocated at a national level against sub-standard equipment. Parents also joined forces nationally in making the case for the necessity of bilateral cochlear implant in Ireland. This necessitated engaging with the media (in both print and broadcast news) and government ministers and TDs. Regardless of the level of advocacy, be it individual or political, parents emphasised that a persistent voice speaking on the child's behalf is essential and explained "if I had done nothing at that stage right, nothing would still be done to this day" (*ITC*, p.239: 23).

k) Raising Awareness

Parents had a crucial role in raising awareness within the wider community. From extended family, to child-minders, to school teachers, to local parent-and-toddler groups, to strangers in a supermarket, to children in a park, to close friends, the parents in this sample were continually asked, and subsequently answering, questions regarding their child's hearing loss. A number of parents described striving to reach a balance between raising awareness while also not wanting to demarcate their child to the extent that they become alienated.

Parents experienced a diverse range of responses in the community. They described encountering people's ignorance, embarrassment, inappropriate comments, over-dramatic responses, thirst for drama and gossip, misunderstanding, and forgetfulness (despite copious explanations). Particularly in the beginning, this often caused parents to feel annoyed, frustrated, cross, or embarrassed in public. In combatting these frustrations, parents often sought to normalise people's understanding of hearing loss, for example explaining to children "Your mammy has glasses because she can't see properly, so [my baby] has hearing aids because she can't hear properly" (*ITC*, p.132: 36–37). Thus, the parent sought to normalise the depiction of hearing loss, by using an everyday analogy.

However, there were also tremendous encouragements in engaging with the community. Many participants described the extent to which their extended family, and specific members of the community (in schools etc.), responded with extraordinary support, effort, and commitment. For example, one family explained that a staff member in community education

> did a sign language course. She actually went and did sign language. It was absolutely fantastic…I was absolutely flummoxed by the length they did, and in their own time, over and above what they needed to do, which I think was absolutely fantastic, and they're a great support for [our child] (*ITC*, p.36: 34–37).

Likewise, many individuals (in parents' extended family/community) actively sought to understand and support the baby and family to the best of their ability, and were very receptive to the parent's explanations and instructions. One parent in particular expressed that her friends, family, and neighbours were her greatest support.

6.5.2 The Influence of the Parent's Role

The participant check corroborated the above classification of parental roles. 100% of parents agreed (57%) or strongly agreed (43%) with the statement that "I have experienced

most of the parental roles described in the presentation" (*PCS*, q.10). The significance of this active participation was highlighted in interviews. One professional stressed that one of the greatest determining factors impacting the outcome for the child is parental involvement. They expressed:

> How much parents are willing to work with their kids, that's huge. That's huge… Parental attitude and parental ability, has a very, very significant impact on the kids outcomes… Parental involvement…I think it a very huge, it is a massive impact on the long term outcome for the kids (*ITC*, p.74: 5-33).

Likewise parents stressed

> You need the parents to be on board. To go through [interventions with the child]… you need the parents' support, the support of the parents. It won't work for the kid if the parents aren't working there with them (*ITC*, p.42: 8–10).

Participants highlighted that parental involvement affects more than language acquisition and access to services, it affects the child's confidence, adaptability, communication, social development, academic achievement, and ability to reach their potential. Significantly, parents in this sample undertook these roles to an exemplary standard, with extraordinary commitment, motivation, and consistency.

6.5.3 Complications in Roles

However, participants highlighted that the implementation of these roles into everyday life is not always simple or straightforward. The following six challenges were identified (direct quotations are used sparingly in the first four sections to protect confidentiality).

a) Lack of Motivation or Undue Motivation

A number of participants identified the danger of a lack of motivation in assuming roles, to the extent that the inactivity negatively affects the child's development as they are not getting

the stimulation they need to reach their potential. Interestingly, parents also described the opposite danger of undue motivation which caused them to feel "paranoid" about reaching milestones (*ITC*, p.109: 31). They described "constantly starting to examine" their baby to the extent it began to overshadow "enjoying" them (*ITC*, p.109: 32–37). It is critical to stress that in identifying this danger, many parents were remarkably self-aware and exercised intuitive self-regulation. Parents often regulated these dangers themselves, but described looking to professionals for validation.

b) Communication is either too simple or too complex

One professional pointed out that parents can sometimes think they are accommodating their deaf child by refraining from teaching them difficult words and giving them simpler language instead. However, this approach, although well intentioned, is misguided as they do not challenge the child to reach their full linguistic potential. Alternatively, parents may struggle to understand how to tailor communication for a child with Hearing Loss, and may engage in a way that is too complex or too fast-paced, or too disordered, or too distant, or without a visual cues, making it difficult for the child to comprehend.

c) Lack of Advocacy or Undue Advocacy

A number of participants highlighted the polarities of advocacy. Parents expressed concern that if a family is unable to advocate (or too shy to seek someone to advocate on their behalf) when they encounter problems, they run the risk of falling between the cracks of the system, being left without the services they need, or with poor equipment, all of which threaten the child's wellbeing. However, in contrast, if advocacy becomes all consuming, the focus of the parent can shift to the cause rather than the actual child, and the child can be lost in the midst of the drive for change.

d) Disengaging from a role

Both parents and professionals observed that there is also a danger that parents completely disengage from a particular role, such as enforcing the wearing of hearing aids. Professionals highlighted that it is critical to seek to understand, and not assume, the reason why parents might struggle with this role and emphasised how effective it is to "listen" to families (*ITC,* p.95: 28). The parents could be struggling because of discouragement at how difficult it is or because the parent themselves battle with the reality of what the hearing aids represent. Alternatively, if the child has a dual-diagnosis, the child may not tolerate assistive technology. One professional, who had worked with families on the cusp of withdrawal and struggling with assistive technology, described how imperative it is to build an affirmative relationship with the parents. She explained "I always will look for what's good in a family" (*ITC,* p.95:40). The professional had the perspective that "I'm there to support them" (*ITC,* p.96:9-10). Within this context the professional described her approach of carefully unravelling and calming the parents' specific concerns, spending time showing the parents how to manage the technology, and encouraging them to wear the assistive technology for a period every day with a view to building it up. The professional described the receptiveness of families who progressed from no use to full-time use in a very short period of time.

e) Sustained Vulnerability

Another important factor impacting the parents' capacity to assume roles is their emotional wellbeing. It is critical to acknowledge that even the most positive parents in the sample, whose children were thriving, still experienced intermittent feelings of grief and loss. This was natural and expected. However, a concern arose for parents with a sustained vulnerability, whose grief remained ubiquitous, or who appeared to have an enduring depression. One family expressed:

> I've seen it, some people just go down and that's it. I've met dads and it's just like, they've given up, you know. They don't want to talk to anybody, they don't want to engage. Their kid is deaf, that's it. And it's absolutely terrible to see it, and to see, I suppose, see the lack of, I suppose, counselling, psychological help that the parents are not, the parents aren't getting it …they don't [even know that they need it] but I mean, that's why there, there should be more of a system there to actually identify it and look out for it (*ITC*, p.31: 6–13).

Likewise another parent emphasised the need for parents to

> have emotional support… [it] is very important because, the mum and dad…face the baby all the time, and ((weeping and inhale)) [so, they] themselves need to be strong first (*ITC*, p.4: 28–30).

Thus, the need to emotionally support the parent during sustained vulnerability is crucial.

f) Conflict in Families

In a two-parent family, conflict can arise between couples as they assume the plethora of roles. Particularly if both parents wish to be actively involved in the child's care, but one parent cannot attend important appointments (due to work schedule), there can be tremendous strain and stress. As one professional explained:

> It's quite frustrating for some fathers, they've to go back to work before the mum and I've seen it. Mum goes up to [important appointments] all the time, comes back down, there might be good news, there might be bad news, but it's always technical. It's always jargon. It's always reports, or audiograms, ABR's and all this. So you've mum who kind of understood what the person…5 hours ago told them, and then they come down and meet dad, and [mum struggles to relay the details]…so you can imagine the frustration that causes, ah I've seen that certainly in families, where that is a big thing. And that is so easy to remedy…having [the professional give a] daily report, or something written down for the parents...Because there is a lot of pressure on the person who's going up [to appointments], and there is also a lot of pressure on the person who isn't available…and that can cause a lot of issues (*ITC*, p.66: 5–22).

A further conflict (identified in interviews) was that of clashing responses whereby one parent who is actively motivated, may feel frustrated and upset by a spouse/partner who is disengaged from assuming applicable roles. However, professionals also highlighted the reverse situation whereby parents "pull together" rather than pull apart, supporting each other in these roles

> When you see parents who work together however, that's the most amazing thing…they help each other out, and remind each other of how to help their kids, rather than, ((critical tone)) "you did that wrong", rather than criticizing. I think where you see parents starting the criticise each other, that's sad, that's hard. But the parents, when they work together, when they pull together, that's just, that's magic (*ITC*, p.83: 39– p.84: 9).

Interestingly, unique struggles were also documented in one-parent families. Particularly if they did not have the support of extended family, the subsequent absence of practical help in shouldering the responsibilities was highlighted as a stress. Furthermore, a professional explained that if a single parent also had other children to care for, they could face practical barriers in assuming these roles as thoroughly as they would like to, which may leave them feeling frustrated or stressed.

6.5.4 The System behind the Roles

While committed, dedicated, supportive, and proficient professionals empowered parents to undertake their roles, it is critical to highlight that a number of the roles arose in response to difficulties parents encountered in the wider healthcare system itself. In particular parents highlighted that the roles of advocating, mediating, and administration largely arose out of necessity to diffuse specific problems they confronted. It is important to highlight that many of these difficulties were as frustrating to professionals as they were to families. The recurring problems, identified in two or more interviews (with both parents and professionals), are succinctly listed in the table on the following page.

Table 6.6 Recurring Problems Encountered in the System

Problem	Quotation from Participant
Under-Resourced Services	They are TERRIBLY understaffed as you can imagine. Oh disaster. I mean the poor things. They really are (*ITC*, p.136: 17–18). I rang in February, no appointment, and the [professional] had gone, and there was no funding there to replace them … [I learned that] if and when they were being replaced, that [my child] would get an appointment (*ITC*, p.237: 31–34).
Lack of Specialised UNHS Training	[A frustration is the] lack of training….come on. It's not hard. Especially with the newborn hearing screening, there's so many new kids coming on board. There's [professionals] all around the country that are just being landed with these newly diagnosed deaf kids, like "what do we do, when do we see them like?" (*ITC*, p.78: 4–6).
Inappropriate Environment/ Facilities	The waiting facilities for the new born screening overall, would be, would be poor... It's all on corridor waiting (*ITC*, p.148: 20–21). Ya I would have sat in a corridor… [when my baby] was maybe 4 or 5 months old for the guts of 3 hours. And…when I say corridor, it's a corridor where you can't really put out your legs because you'd be blocking somebody. The seats are literally, shouldn't be there in the first place…it was a particularly bad experience, I was still breast feeding the baby at the time. And to try to feed a baby, sitting on a corridor, over a number of hours, was not on. And again, yes of course…they have mothering rooms, there is one that I know of in all the lower floor of the [buildings], but you're not going to want to leave because if you're called and you're gone down to the room – so I didn't move from there. I fed the baby and I changed the baby sitting on the corridor, and maybe some people wouldn't have liked me changing the baby, but I was kind of saying, like I'm here and I'm staying until I am called (*ITC*, p.148: 6–17).
Lack of Preparation, **Poor Administration**	Nobody ever told us anything. Like I told them every time what was going on with [my child], they didn't have the time, or whatever, to read [my child's] notes, even before they met us, so they didn't even know what was going on. And they were always looking at [my child's] report, the very first [outdated] report that came from [the newborn stage], they never had any [more recent reports] that were forthcoming from [ongoing assessments] (*ITC*, p.236: 28–32). I don't think some of the charts are being sent to everybody…they all seem to be doing the same thing, but they are kind of not, like sending the charts to one another, they don't seem to know what the other person is doing… So it's kind of frustrating because…like you're only getting so far and like when we go for [appointments]…. It's kind of like, oh, what's the point (*ITC*, p.49: 8–13).
Fragmentation	Within the Irish health system, there's absolutely no connectivity (*ITC*, p.22: 3). It's very disjointed to be honest (*ITC*, p.221: 1).

Lack of a Holistic Perspective	All of this sounds very hap-hazard and random in terms of, you know there isn't a system there to support, the, everything once its explained is very logical or whatever, but there is no system there, I believe to actually, from a holistic point of view to, to care for that child and make sure that that child gets the best of everything, to put them in the best possible position, whatever that position is, and am, I think if there is an improvement, that's where the improvement can certainly be made (*ITC*, p.31: 35- p. 32: 2).
Lack of Collaboration	All of them are very nice, don't get me wrong ((laugh)), all of them when you are dealing with them are very, very nice, but they don't seem to be able to speak to one another (*ITC*, p.238: 12–13).
Geographical Inconsistency	And this is the killer right, there is no consistency right, there is no consistency within the geography of Ireland, but there is no consistency even within the county (*ITC*, p.22: 19–20).
Lack of Collated Information Distributed to Families Consistently Across Ireland	You do get leaflets but that's how you get them, a leaflet here and a leaflet there…and they end up, just I can only speak for myself, in the handbag, the changing bag, kitchen table, work top, put into a file, with the post…They are all individual, am, little things, ya. I've a collection of leaflets, but there is no order to them like (*ITC*, p.170: 10–20).
No Link Worker	There is no one person that you can go to, if you've a child with a hearing loss (*ITC*, p.160: 11–12). There is no one who oversees the whole programme, the overall how the child is doing (*ITC*, p.1432-3).
Limited Hours of Operation	We're 9 – 5, if somebody's working, the chances are there is one carer in the house and the other one is off working. So our supports will focus in on one person, completely and unintentionally, but that's how it is…even though we're flagging it ourselves, we are also propagating it. (*ITC*, p.66: 32–35). [The parent at work] is being left out and there is a lot of pressure on, on the person who does go then to [appointments]… and that can cause a lot of stress (*ITC*, p.66: 29–31).

The grievances captured in the above table represent serious issues within the UNHS system. As outlined in the table, participant's identified manifold problems including the reality of under-resourced services, poor administration, a fragmented system of services, inappropriate environments/facilities for families, the absence of a link worker, limited hours of operation, geographical inconsistency. In addition, the lack of specialised UNHS training, professional preparation, a holistic perspective, professional collaboration, and the consistent distribution of collated information, were recurring problems identified across many interviews. These issues necessitate a resolution.

It is essential to emphasise that as participants identified these problems, there were three important acknowledgements. Firstly, many parents were quick to emphasise their encounters with excellent professionals, many of whom also recognised many of these shortcomings and went over and above the call of duty to try to compensate for these problems (by advocating for the family, linking in with other services, circulating reports or information, a holistic approach, etc.). Many families, and in particular one set of parents, affirmed such dedicated professionals:

> She's just over and above what I'd expect her to do. It's a vocation. It is a vocation. It's absolutely fantastic you know. And the skill set she has is phenomenal (*ITC*, p.44: 19–21).

However, the professionals' capacity to undertake this level of compensation was often strained by the lack of resources and time they were afforded. Secondly, as evident in the participant check, while these problems were certainly common and recurring across Ireland, they weren't necessarily true of every parent's experience. In response to the statement[28] "I have experienced some of the problems in the system" 71.5% of parents within the participant check either agreed (28.5%) or strongly agreed (43%) (*PCS*, q.11). However, it is important to acknowledge that 28.5% of parents strongly disagreed with the statement, indicating they did not encounter these issues (*PCS*, q.11). Evidently, the parental experience of these difficulties varied. In addition many were specific to Stage #4 in particular. Finally, while identifying many of the flaws in the system, families also pointed to strengths, which are detailed in Stage #3 (p. 24). One parent who experienced both the older and newer system of services summarised the contrast potently:

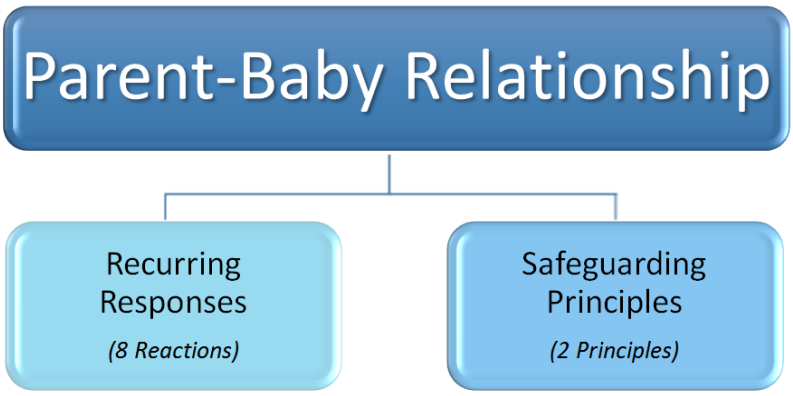
> Obviously they would be very different, and thankfully for the better, they have changed, what I would consider in those 6 years so dramatically, it's, it's such a step forward. But at the same time there is no point in being complacent, of course there is probably changes that could be made to make things better again. I suppose anyone is foolish to think everything is perfect, do you know? There is always room there for improvement (*ITC*, p.167: 9–13).

[28] All statistics were rounded up to their nearest decimal place with the exception of this particular statement to ensure the resultant statistics added up to 100% rather than 101%.

6.6 Parent-Baby Relationship

The four stages of the parent's journey map out the parental experience of receiving an early diagnosis of hearing loss in Ireland. However, the subsequent impact on the parent-child relationship has not yet been addressed. This concluding section will examine this subject exclusively under the two sub-categories illustrated in the diagram below.

Figure 6.6 The Parent-Baby Relationship



6.6.1 Recurring Responses

It was clear from interviews that this developing relationship is affected by the process of receiving and responding to the diagnosis of hearing loss. Analysis of data revealed that while the parent-baby relationship cannot be clinically compartmentalised into four distinct stages, there were nevertheless many common parental responses to their baby, which were often interrelated with one or more stages of their journey. These recurring responses will be examined to conclude this chapter.

a) Testing

One specific response that parents habitually reported during the early stages of their journey was their compulsion to self-test the baby's hearing, This response was most

commonly undertaken in an attempt to either decipher the impending diagnosis (in Stage #1), and to a lesser extent to test the confirmed diagnosis (during Stage #2 or #3). As one parent articulated

> Definitely we would have both tried to slam doors and see if he startled, and do you know did things like that, and we never really got a response, there was one day we thought we had a response, we were on a street and this lorry came by, and he, awakened, but, I think it was actually the vibrations that waked him rather than the noise (*ITC*, p.175: 30-33).

Self-testing was rarely conclusive or satisfactory as parents reported that the baby's compensation (to light, vibrations, smells, etc.) made their responses either ambiguous or else rendered a false sense of reassurance of hearing. One parent also commented that all babies (with or without a hearing loss) sleep through an extraordinary amount of sound, rendering their unresponsiveness irresolute. Nevertheless, this response can pervade parent-baby interaction for a time.

b) Initial Perceptions

For parents with no prior experience of hearing loss, their initial impression of what kind of life and opportunities a deaf person has access to is formed in a vacuum. Many parents described initially perceiving deafness to be debilitating. One family explained

> When you are told that at the time, and you don't have deaf people in your family and you're not deaf, it's devastating, it really is. You don't know whether she will be able to talk. You don't know if she will go to school. You don't have anyone to talk to. You don't even know who to [contact], you kinda think, who will look after her when I am dead (*ITC*, p.30: 8-12).

Parents are overwhelmed by fears that their child will be marginalised and cut off from mainstream society. These early perceptions of deafness can dominate the parent's perspective. As one professional explained:

> They find out that their baby is deaf, and DEAF becomes everything. They stop seeing their baby for a while, they just see deaf (*ITC*, p.69:13-15).

Thus, the parent can initially see their child through their early perception of deafness.

c) *Withdrawing*

As parents grieve the loss of the picture of their baby and life they built up during pregnancy, a natural response can be to withdraw. Two specific manifestations of this were identified across a number of interviews. Firstly, both parents and professionals described the tendency to stop talking and singing to the baby because of the crushing realisation that the baby cannot hear them. As one professional articulated

> Some will just see the diagnosis, ((shocked tone)) "oh my God they're deaf". And they'll sit there and I've had parents say they've just put the baby down ((hands up in the air)) and just sat there. Sure, there's no point doing, in doing, that now, no point singing to them (*ITC*, p.62: 31-33).

Secondly, parents can often feel so upset that they do not want to pick up the baby, as they are so overwhelmed by a sense that they cannot cope with all the baby represents. Thus, the overwhelming grief, particularly in the wake of the diagnosis, can affect the parent-baby interaction for a time.

d) A Lost Celebration

The stress and trauma of the diagnosis (particularly for parents with no prior exposure to hearing loss) can overshadow the celebration and enjoyment of the new born baby. As one professional expressed "it's a celebration, then all of a sudden there's something going wrong" (*ITC*, p.56: 18). In particular parents who experienced a dual diagnosis with medical complications described a compounded sense of this experience and expressed:

> It takes from the whole experience of having a baby...That whole, what you thought was going to be just wonderful, you've been robbed in some ways of the experience, do you know, the really positive experience because there is something wrong with your child...it didn't turn out the way you thought it was going to turn out. Because you do build up a picture in your mind of what it's going to be like…only it doesn't turn out like that. It's, it's, it's very hard you know. And it does. It takes the, I don't know, the whole joy, its tainted a bit like you know (*ITC*, p.219: 3-11).

Thus, the joy and celebration of a new life can be lost amidst the diagnostic process.

e) New Perspectives

After a "period of adjustment" many parents experienced a transformation in perspective (*ITC*, p.69: 34). This typically, but not universally, occurred during Stage #3, and took different lengths of time for different parents. As described in detail previously, some of the critically important turning points for parents are meeting an older deaf child, connecting with other parents, engaging with empathetic professionals, being surrounded by a multi-disciplinary team, receiving timely and coordinated early intervention services, and acquiring positive and hopeful information. This positive input often engendered a redefinition of deafness for parents.

> I suppose it didn't take us too long to kind of realise, this is a normal thing really, in a funny way. And to be thankful that he is completely healthy, it's not like an illness or something…we kind of rationalised it a lot I suppose, and decided that this is going to be something positive. The obvious response we were getting from people is "this is terrible", but actually, is it, you know? It wasn't that bad ((laugh)) you know, once we kind of got our heads around it (*ITC*, p.177: 26-31).

Parents affirmed that with the right supports their child had every opportunity for success, and their potential was not undermined by hearing loss. This nurtured a great sense of restored hopefulness in the parent's perceptions of the baby's opportunities.

f) Proactivity

Equipped with a positive perspective, the majority of parents assumed their roles and responsibilities (outlined in stage #4) in a remarkably proactive capacity. Parental proactivity was strongly motived by the desire to enable their child to reach their potential. One family explained:

> We're going to do everything in her power that will give her that opportunity. We don't want to do anything that will hold her back. So absolutely I will do everything, to make sure that if she wants to do something, then she can do that. That simple (*ITC*, p.39: 17-20).

It was clear within this sample that parental proactivity had the double-effect of cementing intentional one-to-one interaction through play, as well as enhancing the child's development.

> It generally involves going into the sitting room with a box of toys and playing with the toys, and then you go building blocks and "up up up", "down down down", all the animals, role play, I mean they love it, its good craic (*ITC*, p.191: 40 - p.192: 2).

As evident in this quotation, parental proactivity (particularly in the assumption of communication-based roles) had great potential to enhance positive parent-child bonding[29]. Interestingly, by proactively enabling their child to have every opportunity, two families also expressed their endeavour to remove any potential regrets their child may retrospectively feel in the future. As one parent expressed "we want to make sure he can never say, "look my parents never gave me the chance to do that"" (*ITC*, p.185: 19-20). Thus, families worked hard to remove any potential limitations, regrets, and even blame.

g) Pride and Affirmation

With the parents' change in perception, coupled with seeing the child respond positively to intervention, many parents in this sample expressed pride and affirmation of their child's progress. One family were encouraged, detailing how well their children were doing:

[29] The parallel potential dangers are outlined in Stage #4.

> She's taught herself to lip read, right, so we can unplug her as we call it… where she has no sound, and … you can ask her anything you want and she'll have a conversation with you…she'll look at you, she'll answer your questions back or whatever. She's very good, and she did that herself (*ITC*, p.32: 36 – p.33: 5).

Parents described their baby as bright, intelligent, capable, adept and adaptable, insisting there is no need to pity them or feel sorry for them. Indeed some parents even described "we actually forget our child is deaf" indicating their acceptance and adjustment (*ITC*, p.37: 3).

h) Acceptance, Enjoyment and Humour

Parents in this sample expressed a tremendous acceptance and celebration of the baby, insisting "we think she is beautiful just the way she is!" (*ITC*, p.243: 19). One parent in particular expressed enjoying the traits that hearing loss has fashioned in her baby

> It's just part of who he is now, and it's funny as well like there is certain things about him that, if he wasn't deaf he wouldn't have, like he's very visual, and he's very expressive and he signs quite a lot still… if he wasn't deaf he couldn't have a lot of cute things ((smile)). I suppose that's kind of another thing that's helped us come to terms with it. It's just who he is, you know? (*ITC*, p.185: 22-26).

Significantly, across many interviews, the humour, acceptance, and celebration of the baby suggested a strong emotional-warmth in the parent-child relationship.

Reflection on the Responses

The eight responses above were experienced throughout the four stages of the parent's journey. It's important to stress that not every parent described every reaction, nor were they experienced sequentially. However, they represent recurring responses which were repeatedly identified across the spectrum of interviews.

6.6.2 Concluding Concept: Safeguarding Principles

In drawing this Findings Chapter to a close, it is crucial to elucidate the final key concept. As families settle into Stage #4 of their journey, it is essential for two core principles to imbue the parent-child relationship: firstly the parent's unconditional loving acceptance of their baby; secondly the parent's commitment to stimulate their baby to reach their potential. Importantly, these two principles were universally endorsed within the participant check as 100% of parents either agreed (86%) or strongly agreed (14%) with the statement that "I agree with the two principles of parent-child interaction" (PCS, q.12).

Far from being in competition with one another, these two overarching principles are complementary and need to be held simultaneously. It was clear from interviews[30] that difficulties arise if one of these traits are missing. One professional stressed that if parents lovingly accept their child, but refrain from challenging or stimulating them to reach their potential, the child won't develop to their fullest capacity. The opposite scenario was also identified in interviews, if parents are not operating in the context of a loving acceptance, the relationship with their child will be negatively affected. Thus, the unconditional, loving acceptance of the child, and the commitment to challenge the child to reach their potential, are as complementary as they are imperative. They deeply impact the parent-child relationship as well as the child's wellbeing.

6.7 Conclusion

The overarching model of this chapter, depicting the four stages of parental coping with an early diagnosis of hearing loss, represents the culminating conceptualisation of this study. The model was fashioned over months of meticulous analysis of data and each

[30] Direct quotations are not included in this section to safeguard confidentiality

conceptualisation was exhaustively refined with each successive round of data collection, coding and categorisation. However, with the increasing abstraction of concepts, the researcher is in danger of becoming increasingly disconnected from the data. Therefore, to ensure the integrity of this resultant model, parents were invited to give their assessment of its accuracy (through the medium of the participant check). This allowed the researcher to test the trustworthiness of her conceptualisation. Significantly, 100% of parents either agreed (43%) or strongly agreed (57%) that "this model reflects my experience" (*PCS*, q.1). In addition, parents universally agreed (86%) or strongly agreed (14%) that "the model is a helpful illustration of my journey" (*PCS*, q.2). Therefore, the conceptual framework of this study, is both *grounded* in participant data, and substantiated by participant evaluation.

7. Discussion

7.1 Introduction

Having completed the analysis of data and fashioned a conceptual framework, one task remains. The constant comparison technique intrinsic to GT methodology necessitates the final endeavour of contrasting this resultant conceptualisation with the body of literature. This objective represents the endeavour of this Discussion Chapter. While implementing this directive, the researcher discerned three levels of comparison, between the concepts of her study and the literature, which she classified as:

1) Complementary Concepts: many of the individual components embedded within the Findings Chapter are concurrent with the wider body of literature.
2) Unique Concepts: a number of concepts within this study appear to be largely unaddressed in published literature.
3) Contradictory Concepts: specific findings of this study conflict with particular publications.

While considering the significance of her conceptual framework, one stage at a time, the researcher will unobtrusively weave these three levels of comparison into her analysis.

7.2 Stage #1 Anticipating: The Debate of Early or Late Identification

With the inception of UNHS in Ireland, the first stage of the parents' journey (named *Anticipation*) now commences in the immediate aftermath of the baby's birth. This change represents what Kurtzer-White and Luterman (2003) classify as a *paradigm shift* from a later to an earlier diagnosis. Participants in this sample universally welcomed this *paradigm shift*. This affirmation was evidenced within the participant check as 100% of parents either agreed (29%) or strongly agreed (71%) with the statement that "early identification of hearing loss has benefitted my child" (*PCS*, q.15).

This endorsement was also evident within individual interviews. Early identification and intervention was corroborated from four separate vantage points. Firstly, parents who experienced both an early and late diagnosis of hearing loss were among the strongest advocates for UNHS, insisting that their distressing experience of a later diagnosis and delayed intervention "should never happen to any child" (*ITC*, p.147: 37) . Secondly, parents who only had experience of an early diagnosis affirmed UNHS unreservedly. One parent expressed that the same diagnosis at a toddler stage "would be 10 times harder" (*ITC*, p.177: 9 - 10). She explained that without UNHS any suspicion of hearing loss would have been camouflaged by the child's remarkable compensation:

> If you are walking behind him, he will <u>always</u> turn and look at you… because there is light coming from behind you, and there is a small shadow moves up a tiny bit like that, he knows there is someone behind him you know…and if he's asleep you have to be so careful walking into his room because if there is a slight change of light or if he feels a draft, he's going to be straight up…so it's funny like, you definitely would have difficulty diagnosing it, or picking it up [without UNHS] (*ITC*, p. 190: 31-38).

Consequently, this parent stressed that "it's been so worth it…if there was no newborn screening, we'd probably wouldn't have <u>started</u> the process yet" (*ITC*, p. 190: 25-26). Thirdly, parents who received a dual-diagnosis explained that, without UNHS, any signs of hearing loss would have been attributed to the cognitive impairment of the child, thereby inordinately delaying, or altogether missing, the recognition of the child's hearing loss. Finally, professionals in this sample also observed that as a consequence of the child's more established personality, a later diagnosis can represent a greater identity shift and transition for families. As one professional observed:

> With newly borns I suppose, parents I think at that stage, have a huge capacity for change already...Whereas for a 2 year old or for a 1.5 year old that can be a shock, because the child has a personality, and suddenly…it's like a different [child], it's like a switch (*ITC*, p.63: 27-35).

Professionals who had supported families though both early and late diagnoses observed that parents with a later diagnosis were "actually more traumatised" (*ITC*, p.85: 25-26). Thus, the

consensus was unanimous among this research sample, that the absence of UNHS would have compromised the child's development and caused more distress to parents later on.

While Kurtzer-White and Luterman (2003) affirm the developmental advantages of UNHS, they express specific concerns for parental wellbeing within the context of an early diagnosis. They suggest that:

> Parental coping has been changing with the inception of newborn screening as we move from a parent-initiated model of diagnosis to an institution-initiated model. Coping now begins without any preparation, and without any time for parents to "enjoy" their child as "normal." (Kurtzer-White & Luterman, 2003, p. 232).

This quotation encompasses three distinct issues in relation to UNHS: firstly, the loss of control incurred by an institution initiated model of diagnosis, secondly, the lack of parental preparation, and thirdly, the absence of time to enjoy the new-born baby free from anxiety. It is crucial to address each of these concerns in turn.

Firstly, Kurtzer-White and Luterman's contrast of the "institution-initiated model" versus a "parent-initiated model" of diagnosis is imbued with connotations of empowerment (2003, p.232). The "parent-initiated model" implies that parents are more in control of their child's diagnosis as they initiate the process. The contrasting "institution-initiated" model which encompasses a systematic and universal screening programme infers a sense of parental disempowerment. However, these implications are misleading. Within this study sample, a parent of an older child with PCHI (who received a later diagnosis in the absence of UNHS) experienced what can be classified as an "Independent Awareness" as she perused a diagnosis in Stage #1 (see section 6.2.2 of the Findings Chapter). While this parent gradually and independently came to the conclusion that her older child had a hearing loss, she encountered professional denial which inordinately delayed the suspected diagnosis. She had to resolutely advocate for basic diagnostic services and battle unreasonable structural delays in the struggle to access intervention for her child. She grieved not only the absence of an institution-initiated

model of diagnosis, but also the lack of a timely early-intervention system to support her child. The parent expressed:

> We felt aggrieved that we had already lost [so much time] and it wasn't fair on him…there was only one thing going to hold back this child and that was that he couldn't hear in the early days…those formative years when it was all so important to learn the language he had missed out…There was something wrong with [the older] system…it wasn't on…Not in the late 2000's…it should never happen to any child, with any diagnosis. There was something wrong in the system to have skipped him. So ya, to compare that, to fast forward [a number of] years later, finding ourselves in a maternity hospital where a 2 day old baby was picked up…you could only describe that as an improvement that is almost immeasurable….it was such a different experience (*ITC*, p.147: 31-43).

Thus, far from feeling disempowered, these parents felt more supported by a coherent institutional-led diagnosis, particularly when accompanied by an accessible and coordinated early intervention system of services.

Secondly, the findings of this study also counteract Kurtzer-White and Luterman's (2003) assertions with regard to parental preparation. Kurtzer-White and Luterman (2003) imply that a later diagnosis of PCHI incorporates greater anticipation and preparation, as parental suspicions are gleaned over time as they recognise signs of hearing loss. However, this is not universally the case. Two research participants (who also received a later diagnosis of an older child) experienced what the researcher classified as an "Abating Awareness" during Stage #1 (see section 6.2.2 of the Findings Chapter). Although these parents initially suspected a hearing problem, the absence of UNHS coupled with the child's remarkable compensation camouflaged any lingering evidence of a hearing loss. These parents' early suspicions were abated, not augmented, with time. When the child was eventually referred for diagnostic testing, the parents conjectured there was just a middle ear problem and neither suspected, nor anticipated, the possibility of a significant hearing loss. The subsequent diagnosis was shocking to the parents who were not prepared for PCHI. Furthermore, in the same way a later diagnosis is not necessarily anticipated by parental suspicions, an early diagnosis is not necessarily abrupt

or unforeseen. The circumstantial cues (of repeated screening and subsequent diagnostic testing), as well as the clinician's ongoing explanations, are crucial in creating a sense of context for families which fosters preparation (detailed in section 6.2.3 of the Findings Chapter). Although this anticipation is precipitated by external forces (rather than by parents' independent suspicions) it nevertheless cultivates an expectancy for an impending diagnosis. The clinician's responsibility in this regard is crucial.

Finally, this research also challenges Kurtzer-White and Luterman's (2003) concern for parents to enjoy their new-born baby free from the worry and grief of a diagnosis (Kurtzer-White & Luterman, 2003). Before providing a counter argument, it is important to acknowledge that this concern is raised in a number of articles, including Fitzpatrick et al's study (2007) which cited a parent's preference to receive the diagnosis a little later, to allow time to "bond with their child as 'just a baby' and to adapt to just being a mother first" (p.101). However, Fitzpatrick et al (2007) detail that this represented the perspective of a "few" parents, rather than a universal consensus among their sample (p.101). They also stress that "all parents concurred that the efforts to detect hearing loss at the very earliest age should be continued" (Fitzpatrick et al, 2007, p.101). The parents in this study, who experienced a later diagnosis, did not appear to cherish the early memories whereby they were unaware of their child's hearing loss. Rather they were often burdened by retrospective regret and described:

> We were kicking ourselves. And we were reanalysing it. And we were beating ourselves up over the fact that, why did we not [realise she was deaf]? (*ITC*, p.33: 5-6).

The longer period of time for families to "enjoy" their baby free from the stress of a diagnosis, was not retrospectively cherished by parents in this sample, and appeared to incur even more emotional distress later on. This is corroborated in the same article penned by Fitzpatrick et al (2007) who observed that far from cherishing the pre-diagnostic phase, some parents who received a late diagnosis of the child's hearing loss retrospectively "mourned" that their child's

needs were not fully met in infancy, grieving that their baby "did not have full access to her environment in the early period of life" (Fitzpatrick et al, 2007, p.105). They confirmed that the crushing emotions of grief and guilt, were coupled with the stress of language delay, the strain of catching up for lost time, and a sense of regret (Fitzpatrick et al, 2007).

This study research therefore challenges Kurtzer-White and Luterman's three concerns with regard to UNHS (2003). It is unsurprising that rather than representing an actual research endeavour, Kurtzer-White and Luterman's (2003) article is written from the vantage point of a literature review, which seems to be informed by their own professional expertise. While many of their general principles are applicable and valuable, these specific concerns regarding UNHS appear to be founded in conjecture rather than evidence.

This criticism cannot be applied to all their literature. An earlier article penned by Luterman and Kurtzer-White (1999) is founded upon the execution of substantial field research. However, the sampling of this particular investigation is problematic as the study targets a broad spectrum of parents of children aged 3 months to 24 years without classifying the percentage of participants who received an *early* or *late* diagnosis of their child's hearing loss. This ambiguity results in the lack of differentiation between the perspectives of parents within these two diverging categories. Their resultant article is therefore not representative of parents who specifically receive an *early* diagnosis of hearing loss (Luterman & Kurtzer-White, 1999). Consequently, while Kurtzer-White and Luterman certainly presents an insightful treatment of parental coping with hearing loss *in general,* they do not appear to be attuned to the unique dynamics of parental coping with an *early* diagnosis of infant's hearing loss in particular (Kurtzer-White & Luterman, 2003; Luterman & Kurtzer-White, 1999). While there are certainly challenges facing parents who receive an early diagnosis of hearing loss (which are detailed throughout the Findings Chapter), Kurtzer-White and Luterman's (2003) treatment of the subject lacks exactitude.

7.3 Stage #2 Confirming: The Dynamics of Grief and Support

One of the most important findings of this study was the complexity of the parents' emotional response to the diagnosis. It was clear throughout the interviewing process that receiving the diagnosis of hearing loss does not occur in a vacuum for parents. Their experience can be affected by numerous factors including:

- Postnatal depression
- Family circumstances
- Additional diagnoses (potential or confirmed)
- Family history of hearing loss (either its absence or presence)
- History of loss and trauma (e.g. having previous miscarriages, recent family funerals)
- Cultural attitudes towards differences or perceived disabilities (e.g. Irish, International, or within the Deaf community)
- Family dynamics (spousal relationships as well as wider family dynamics)
- Personality of the parent (positive/negative disposition naturally)
- Degree of hearing loss (while this can have a bearing, it often does not correlate with the intensity of grief or hopefulness families experience)

These factors (among many others) can augment or alleviate parents' experiences of grief. Thus while grief is a complex response, the factors impacting it are similarly multifaceted.

While there are a number of articles which provide an in-depth exploration of parental grief, the majority of literature does not deal extensively with the question of how parents manage their overwhelming grief in the wake of the diagnosis, or the process by which they learn to adjust and cope. Even the exceptional articles which do consider this subject often provide an insufficient treatment of the issue. Six articles authored by Md Daud et al (2013), Hintermair (2000), Feher-Prout (1996), Yoshinaga-Itano (2003), Young (1999), and Kurtzer-White and Luterman (2003) are considered below to corroborate this assertion.

Firstly, Md Daud et al (2013) explore gender differences in coping styles. This research is executed by a quantitative Brief COPE Scale questionnaire consisting of 28 topics which parents rated according to a four-point Likert scale. While this research provides valuable

information and considers a range of coping mechanisms, they are nevertheless predetermined by the quantitative questionnaire. This *a priori* approach appears to inhibit parents own identification of alternative coping mechanisms which they themselves considered to be significant during the aftermath of the diagnosis. The closed questionnaire also restricts an in-depth exploration of the way in which the coping mechanisms were specifically manifested or employed to manage grief. This approach stands in stark contrast with the qualitative, inductive, and emic research design of this current study.

Secondly, Hintermair (2000) examines the impact of social support on parents' level of stress and coping. However, this investigation does not refer to the point of diagnosis. The average age of the child at the point of parental participation in the study was 6.6 years, as opposed to new-born. Consequently, the findings of this study are not specific to the unique dynamics of managing overwhelming grief in the immediate wake of the diagnosis of hearing loss. Similar to Md Daud et al's (2013) research, Hintermair's, (2000) study was undertaken with two quantitative questionnaires (including the generic "parent stress index") which focus on a restricted number of predetermined factors (Hintermair's, 2000, p.44). As well as representing a flat, one-dimensional perspective of stress and coping, the participating parents do not appear to have been given the opportunity to direct the investigation with their own identification of the significant coping mechanisms intrinsic to their experience. In contrast, this present study employed semi-structured interviewing as the primary means of data collection, to ensure that the participants themselves guided the study.

Thirdly, an older article penned by Feher-Prout (1996) entitled "Stress and Coping in Families with Deaf Children" provides a comprehensive breakdown of the classifications of coping mechanisms. However, this article is fashioned on the basis of a literature review rather than on the basis of field research. In addition, many of the articles which are referenced appear to predate neonatal hearing screening (e.g. Berstein and Barta, 1988, Calderon, 1988, Calderon,

Greenberg and Kusche, 1989). Furthermore, Feher-Prout's (1996) analysis of stress and coping is not focused on the post-diagnostic period but provides a broad analysis which includes later issues such as schooling. Thus, the article is not attuned to the unique dynamics of parental coping with an early identification of infant hearing loss in the aftermath of receiving the diagnosis. Significantly, this study specifically concentrated on the diagnostic period, with a view to provide an in-depth analysis of this phase in particular.

Fourthly, Yoshinaga-Itano (2003) addresses the question of grief resolution. She asserts that "families with early-identified children resolve their grief faster than families with later-identified children as long as their children develop strong language and communication skills" (Yoshinaga-Itano, 2003, p.205). However, there are two difficulties with this assertion. Firstly, the idea that grief may be absolutely resolved is refutable. It was clear within this study that although the initial force of grief generally eased over time, even the most well-adjusted families continued to experience intermittent feelings of loss. This observation is corroborated by a number of authors in the literature review, including Kurtzer-White and Luterman (2003), Young and Tattersall (2007), as well as Russ et al (2004). Secondly, Yoshinaga-Itano does not explore the particular ways in which parents work through their response to the diagnosis and come to the point of being able to "move on with their lives in their thinking, actions, and emotions" (2003, p.205). Consequently, there appears to be both an acknowledgement that parental coping with grief is a "central concern" and yet, paradoxically, an oversight as to the particular coping mechanisms parents employ or how they are specifically manifested in the context of UNHS (Yoshinaga-Itano, 2003, p.205). This current study sought to address this oversight.

Finally, a number of authors present isolated factors which may impact parents' experiences of managing grief. For example, Kurtzer-White and Luterman (2003) highlight the tendency to seek therapies that are perceived as a cure which may temporarily cause the parent

to suspend their grief. Young (1999) discusses the impact of worldviews on parental perceptions and adjustment to their child's hearing loss (1999). In presenting these isolated factors, neither author asserts that these issues are definitive or comprehensive in understanding the complexity of the parent's struggle to manage grief. However, herein lies the problem: individual articles often focus on one to two components of coping which are not situated within a comprehensive exploration of the numerous ways in which parents manage their overwhelming grief. In contrast, this study sought to provide an overview of the range of parental responses during each stage of their journey.

Despite its limited treatment in the literature, a number of authors affirmed that "parents' grief and coping skills…are a significant variable in the equation of attaining positive outcomes for children with hearing loss and should be an essential consideration in intervention services and programs [Meadow-Orleans, 1994; 1995; Yoshinaga-Itano and de Uzcategui, 2001]" (Kurtzer-White & Luterman, 2003, p. 232). Consequently, within this study, the parent-identified means of coping during the aftermath of receiving a diagnosis is an important finding. The specific parental responses which the researcher classified as restraining, withdrawing, releasing, denying, seeking solidarity, redefining encounters, rationalising, and proactivity (detailed in section 6.4.3 of the Findings Chapter) represent an original conceptualisation depicting a variety of coping mechanisms specific to UNHS. This not only provides an insight into the parental process of managing grief but also enables professionals to carefully understand and compassionately engage with parents as they respond to the diagnosis.

It was clear from this study that the professionals surrounding the parents, have a critical role in supporting parents through periods of acute vulnerability. The clinician in particular, is the only professional engaging with parents during the latter half of Stage #1 and during Stage

#2 of their journey. Therefore, the necessity for them to synchronise their clinical expertise with compassionate counselling skills is essential. As one parent in this study expressed:

> They need to [show] concern…[for] the parents' emotions as well ((voice breaking with emotion))…the dialogues [and conversations with the clinician], they are very important because we just talk to them in the beginning, just see them in the beginning…if they could pass their care ((voice breaking with emotion)) to the parent, that would be a lot better. Not just the result (*ITC*, p.9: 10-16).

This appeal was substantiated within the participant check of this study as 100% of parents either agreed (86%) or strongly agreed (14%) that "hearing loss professionals should be trained to support parents emotionally" (*PCS*, q.6).

The literature also corroborates this assertion. Parents across numerous studies emphasise the need for professionals to have empathetic and adept listening skills, and provide emotional support during the acute vulnerability of the diagnostic period (Russ et al, 2004; Luterman, 1999; Minchom et al, 2003; English & Archbold, 2014). In the voice of one parent in Luterman and Kurtzer-White's study, the clinician needs to "be prepared to deal with the emotional ramifications of the news they deliver" (1999, p.17). Significantly, the Findings Chapter of this study nuanced this recommendation, highlighting that different parents prefer different degrees of compassionate engagement (detailed in section 6.2.4 (d) of the Findings Chapter). However, even the capacity for the professional to discern the appropriate level of emotional support to offer to families represents a judicious counselling skill.

Luterman and Kurtzer-White (1999) strongly argue that the current level of training audiologists receive in counselling is not sufficient in adequately preparing clinicians to deliver difficult results in a sensitive and compassionate manner and deal with resultant emotional vulnerability (1999). They point to a study undertaken by Crandell (1997) which "surveyed audiology training programs and found that only 18% of audiologists ever take a counselling course" (Luterman & Kurtzer-White, 1999, p.17). With this lack of training Gibley (2010)

highlighted that clinicians "have been shown to lack both confidence and skill" in communicating the diagnosis and found that "50% of parents expressed dissatisfaction with the process of the breaking of bad news" (p. 265). Luterman and Kurtzer-White critique this serious deficit in audiological training, emphasising that the acquisition of counselling skills should be prioritised and "considered critical to attaining diagnostic expertise" (Luterman & Kurtzer-White, 1999, p.17) Significantly, this imperative is not only a question of best-practice principles but also represents an ethical obligation, as clinicians should be "well trained in the emotional impact of the news" they deliver (Luterman & Kurtzer-White, 1999, p.16, 17). It was clear from this current study that the imperative to have adequate training in counselling skills, is not just an important recommendation for the clinician, but for all professionals engaging with parents during periods of acute vulnerability.

7.4 Stage #3 Adjusting: The Hope of Early Intervention

Young and Tattersall observe that with early intervention, the hope of normalisation is potent (2007). Within the context of this current study, a word count revealed that the word "*normal*" occurred 89 times in interviews with participants. Its use was multifarious as it was often employed to refer to a "normal pregnancy", "normal birth", settling into "normal life", "normal service delivery" etc. However, it was also employed within the specific context of hearing loss. Upon receiving the diagnosis, parents initially feared that hearing loss represented a threat to normality, expressing that, "you worry about…[your baby's] future, whether they will have a normal lifestyle" (*ITC*, p.5: 27-28). As another parent explained, "we didn't know <u>what</u> kind of future [our daughter] would have. Would she be able to <u>speak</u>, would she go to school?" (*ITC*, p.16: 2-3). The implication across many interviews was that a "normal lifestyle" involved aural speech, mainstream education, and having the capacity to engage

freely with their surrounding family, community, and culture without being alienated or marginalised (*ITC*, p.5: 28). It was often very hopeful to parents when these possibilities of aural speech and mainstream education were regained, and indeed this was many parents express desire for their children.

Young and Tattersall interpret this desire in an ideological capacity depicting it as indicative of a particular worldview (2006). Drawing on their analysis of interviews with 27 families in the UK, they observed that parents in their sample articulated the same hopeful anticipation "that their child would reach what they regarded as normal developmental milestones" which encompassed being "able to manage successfully in mainstream education on a par with their hearing peers" (Young & Tattersall, 2006, p.215). Parents in their study also aspired that their child would achieve "normal speech development" (Young & Tattersall, 2006, p.218, 215). Young and Tattersall translated this aspiration for normality in speech and schooling to mean "as if hearing" and highlighted the recurring associations with the medical model of hearing loss (2006, p.218). They argued that the perspective of the medical model (which depicts hearing loss in a purely clinical terms as a negative deficit to overcome) informed these parents' earliest exposure to their child's diagnosis (2007). In an earlier article, Young argues that as a consequence of this worldview, the process of parental adjustment to their child's hearing loss, "is essentially about management and recovery from something that has gone wrong and is damaged" (Young, 1999, p.158).

In combatting this clinical perspective Young advocates the alternative worldview of the cultural-linguistic model (1999). She explores how the cultural-linguistic model of deafness offers an "anti-tragedy, culturally diverse, linguistically able approach to deafness" which "radically challenges many of the loss and disruption concepts that underpin traditional views of the adjustment process" (Young, 1999, p.157). Within this worldview what it means to have a hearing loss is promoted in a "radically new" way, as a positive difference rather than a

negative deficit (Young, 1999, p.157). Young argues that in responding to the news of their child's hearing loss through this lens, "parents are not engaged in a process of adjusting to a damaged version of `normal' but to a different version of `normal'" (1999, p.160). Consequently, "the characteristic of the deaf child `not being like us' is not something to be mourned over, but to be accepted as a positive attribute" (Young, 1999, p.160). This "anti-tragedy" perspective of hearing loss celebrates the richness of sign language and the unique culture and heritage of the Deaf community (Young, 1999, p.157).

However, Young and Tattersall's (2006) ideological interpretation of the term normalisation, to be indicative of a particular worldview, is refutable. Within this study the parental aspiration for verbal age-appropriate language and mainstream education, seemed to be a concern for opportunity and social inclusion, rather than a question of identity. In addition, while striving for aural language and mainstream education, many parents in this sample simultaneously engaged with a sign-language tutor and a number were also actively involved in their local Deaf community, regularly interacting with many Deaf role models. Many parents desired to give their child the best of every opportunity and were not confined to either a medical model or a cultural-linguistic model as if the two worldviews were mutually exclusive. In addition, the participants' use of the word normal did not universally signify "as if hearing" (Young & Tattersall, 2006, p.218). This is clearly evidenced in the sentiments of one parent:

> He's helped us to cope as well because he's just so normal ((laugh))…it's just part of who he is now and it's funny as well like there is certain things about him that, if he wasn't deaf he wouldn't have, like he's very visual, and he's very expressive and he signs quite a lot still, am, but, ya, it's just part of who he is, if he wasn't deaf he couldn't have a lot of cute things ((smile))…It's just who he is you know (*ITC*, p.185: 21-26).

In this quotation "normal" indicates a positive difference that is embraced and enjoyed by the parent. For other parents in this sample, the use of the word "normal" was simply employed to refer to that which was familiar or expected. In addition, the researcher named the fourth stage

of her model *Normalisation*, which she defined as the return to everyday life. Thus, the findings of this study challenge the ideological interpretation of parental desires for normality and undermines the polarity of a medical and cultural-linguistic model (2007).

This current study is not the first to challenge this dichotomy of worldviews. Young's article (1999) elicited two important responses. Firstly, Flo Canavan, a parent of a child with hearing loss, responded directly to Young's article. While affirming many features of the cultural-linguistic model Canavan highlighted that (when held exclusively) it risks overemphasising the politics of identity (1999). She argued that it "puts pressure on parents to hide their true feeling" and deny their anguish, bewilderment, and vulnerability (Canavan, 1999, p.173). In addition, she identified that parents may feel a pressure to "pretend they are happy" and may supress their grief as they daily encounter reminders of the "difficulties and emotional upsets that are created by the child's deafness" (Canavan, 1999, p.173). She also highlights that, in the early stages of their journey, the cultural-linguistic model will typically be alien to parents of newly diagnosed children and the "political stance of this new approach" can carry a "pressure to conform" (Canavan, 1999, p.174). Significantly, Canavan does not reject the cultural-linguistic model, as she affirms and embraces many aspects of it, but she certainly highlights its dangers when held exclusively.

Likewise, Peter Hindley (a psychiatrist) directly responded to Young's article (1999) advising caution. He protested that the parental sense of loss is not necessarily a result of "pathologising" the deaf child (Hindley, 1999, p.175). He argued that even within the positive perspective of deafness (as a difference rather than a deficit), the diagnosis nevertheless is an unexpected event which inevitably encompasses a sense of loss. He warns that "failing to recognise the sense of loss entailed for parents brings the risk of driving feelings of loss underground because they are seen as unacceptable" (Hindley, 1999, p.175). This can be harmful to the parent, child, and family. However, far from discarding the cultural-linguistic

model, he affirms that there are times when it is both healthy and healing to celebrate the positives of the child's deafness, embrace the child's potential, and challenge the sense of disruption or difference it causes. While these "coping mechanisms are appropriate for different moments and situations", they should not be employed repressively in a manner that rejects an acknowledgement of loss and denies the need to grieve (Hindley, 1999, p. 176). It is essential to highlight Young's remarkable academic integrity in her decision to include both of these critical responses in the appendices of her journal article.

As evidenced by this inclusion, Young was not oblivious to the difficulties of the cultural-linguistic model (1999). By incorporating both Peter Hindley and Flo Canavan's responses in the appendices of her journal article, she affirmed their perspectives and acknowledged their contentions. Furthermore, within the body of her article, she also observed that for some parents in her study the cultural-linguistic model caused more anxiety than reassurance (1999). Young therefore offers a nuanced treatment of the subject. However, it is important to also recognise that the counter-dangers Young highlights regarding the medical model are confirmed by authors such as Luterman (1997). Luterman affirms that, when deafness is approached in a purely clinical manner and portrayed as a negative deficit, "a critical area of self-esteem" is undermined and assaulted (Luterman, 1997, p.1). This implicitly devalues the dignity of the individual, implying that they are somehow defective. Thus, there are dangers associated with holding either the medical or the cultural-linguistic worldview exclusively.

In responding to the ideological divide between the medical and cultural-linguistic models of hearing loss, Mattijs et al (2012) resist the politics of polarity, and propose a new paradigm. They identified the "emergence of a new discourse, one that is neither purely medical nor cultural-linguistic but embraces both discourses" (Mattijs et al, 2012, p.398). This more holistic framework offers families "the opportunity to benefit from both approaches" and

dismantles the divisiveness of an "either/or" approach to the services available to families (Mattijs et al, 2012, p.398). This guards against imposing highly-charged ideological decisions upon families (with regard to alternative early intervention pathways) while they are in an emotionally vulnerable state of mind. It also presents families with the best of both worldviews. Interestingly, Young also acknowledged this hybrid model which she classified as a "bilingual" or a "bicultural" approach (1999, p.159). She proposed that this bilingual-bicultural ethos is achieved by programmes which integrate the following three "distinguishing features" into their early intervention services (Young, 1999, p.159):

1) Offering families the opportunity to learn sign language
2) Providing access to Deaf role models
3) Promoting a positive perspective of Deaf culture and community.

Significantly, offering these three cultural-linguistic features to families does not signify a rejection of audiological services, but rather an integration of both clinical and cultural approaches to early intervention.

Importantly, this bi-lingual approach seemed to represent the experience of a number of parents who participated in this study. One set of parents who were actively involved with the Deaf community explained their rational for choosing to engage in both speech and sign:

> Every week religiously the teacher comes out and we do the sign language, and we are teaching the kids sign language...our logic is, were letting [our child] make up her own mind for what she actually wants to do and give her as much options as we can (*ITC*, p.36: 17-21).

In addition, another family who considered withdrawing from sign language classes to focus exclusively on aural communication changed their mind on the advice of their audiologist, visiting teacher, and speech and language therapist, each of whom encouraged the family to continue learning sign, advising that it would yield only positive benefits for the child. In addition another mother expressed her admiration for a Deaf role model in her life:

> She is an amazing person, she would certainly would be able to lip read a little bit, and she has sign language… [She is a] lovely person and…has obviously got through life really well, and she is an inspiration to anyone that may have a child that is profoundly deaf (*ITC*, p.162: 2-5).

Thus, a number of families in this sample embraced many aspects of the cultural-linguistic model, which did not conflict with their employment of assistive technology, their effort to teach aural language, or their engagement with mainstream education.

It was evident that this bi-lingual model was encouraged by many professionals in this sample as they supported parents. As one professional articulated:

> What we need is communication…We need [the child] to have Language of some kind. Just because he learns sign language first does not mean that it holds back his spoken language, in fact often the use of sign can stimulate spoken language later. As he grows and develops, he will gravitate towards the version that's most easy for him. So we've a lot of kids who would start off signing and would then end up being more of a speaker than a signer, and we've a lot of kids who rely…equally on both, and then we've some kids for who the speech doesn't really work out, so their predominant method of communication is sign (*ITC*, p.80: 35 – p.81: 2).

Significantly, professionals within this sample treaded carefully when addressing this subject. It was clear from interviews that while many professionals sensitively encouraged bi-lingual engagement, they respected the parents' choices to engage or withdraw from these opportunities without exerting undue pressure on them. Thus, the professionals in this sample advocated a gentle bi-lingual approach rather than a forceful one. However, it is unclear if this approach is consistent across all early intervention services in Ireland.

While endorsing a bi-lingual approach, it was evident throughout this research that the biggest threat to the child's development is not a family's potential selection of one form of communication over another. Professionals highlighted that the greatest issue would be if a family withdrew from all modes of communication intervention entirely and the child was not supported to learn language of any kind (be it sign or speech):

> If somebody, and I've never had it happen, touch wood please God I won't, but if somebody was to pull out of the system entirely and say, "I'm out", it becomes an issue of child neglect. And then you have to get social work involved ((concerned tone)). You know if a child is not making his appointments for anything, and it is neglect. And like I think that is the last thing that a parent in that position wants visited upon them…But thanks be to God, it's never come to that (*ITC*, p.77: 9-15).

Interestingly, there does not appear to be a social work professional (who specialises in hearing loss) specifically allocated to working within the HSE early intervention programme for hearing loss. Rather, the social worker employed by community Charities seem to be the point of contact as difficulties arise. One participant in this sample emphasised that the early intervention services shouldn't wait until there is a crisis until a referral to social work or to a charity is made. Rather, if this generic support were habitually offered to all families from the outset, this input could circumvent a problem escalating to a crisis. Furthermore, even if a situation of neglect arose despite this early support, the social worker's prior relationship with the family could provide a more constructive context for addressing issues and working towards a positive resolution.

7.5 Stage #4 Normalising: The Significance of Parental Proactivity

Parental involvement was identified within this study as one of the most important influences in the child's development. This affirmation is consistently substantiated within the body of published literature. Young et al (2009) assert that "the effectiveness of early intervention depends to a very great extent on its reception by families (not its provision)" (p. 433). Likewise, Des Georges affirms that "the success of children who are identified to be deaf and hard of hearing is critically impacted by parent's reactions, acceptance, and advocacy for their child" (DesGeorges, 2003, p.89). Similarly, while promoting the value of the parents' role, Luterman emphasises one older longitudinal study undertaken by Schlessinger (1992)

which tracked 40 families over a 20 year period. This study proved that the greatest determining factor influencing the child's literacy skills was the mother's sense of empowerment (Luterman, 1997; Schlessinger, 1992). This was more significant than the socioeconomic status of the family, the child's level of hearing loss, or even the educational philosophy (Luterman, 1997; Schlessinger, 1992).

However, while these publications affirm the importance of parental participation, they do not specifically define the diversity of the parents' roles (Young et al, 2009; Des Georges, 2003; Luterman, 1997). As Kurtzer-White and Luterman observe, "although all researchers would agree that the role of the parent is critical", there is nevertheless "little research evidence as to the role that parents actually play in support of their child's development" (Kurtzer-White & Luterman, 2003, p. 232). Consequently, the researcher's specific identification of the eleven roles parents undertake (actively engaging with services, ongoing learning, reinforcing intervention, managing technology, ensuring use, monitoring, administration, mediating, networking, advocating, and raising awareness) appears to be unique to this study.

Parents in this sample took on the eleven roles to an exemplary capacity. Their implementation of these roles were consistently underlined by their unmatched commitment to the child (earnestly desiring what is best for them), their initiative (seeking out creative solutions such as hearing halos), their competence (in managing technology), their comprehension (in learning the discipline), their high motivation (in implementing the roles to a very high standard), their resilient attitude (firmly believing the child can reach their potential), their persistence (to keep going when they may see no change initially). Parents in this sample also gave an extraordinary amount of time, resources, and involvement (building roles into their everyday routine), and consistently championed their child's best interests. It is critical to value, affirm, and celebrate this because the subsequent benefit for the child is

immeasurable. As one professional in this sample rightly expressed, "I…have huge respect for parents" (*ITC*, p. 100: 25).

While Young and Tattersall (2007) affirm parental involvement, they advise caution when addressing the subject of parental proactivity. In their interviews with parents, Young and Tattersall (2007) observed that the greatest reassurance parents derived from the early identification of hearing loss is the prospect of taking timely action and accessing intervention at the earliest possible point of the child's life to the benefit of the child's development and maximising their potential. While acknowledging that the sense of empowerment parents feel by assuming control may be "helpful in resolving distressing psychological reactions (such as grief)", Young and Tattersall advise reticence, cautioning that "a focus on activity" may cause parents to "avoid or deny feelings that are important in the process of coming to terms with an event that has disrupted an expected life pattern" (2007, p.217). Kurtzer-White and Luterman (2003) also articulate the same concern, cautioning against parents suspending the process of coming to terms with their grief by pouring their energy into interventions with the hope of "fixing" their child (p.234). They emphasise that in this predicament "parents may never deal directly with their feelings but are doomed to disappointment because technology does not 'cure' the deafness or the child's difference" (Kurtzer-White & Luterman, 2003, p.235).

A number of parents in the sample of this study spoke about the relationship between their grief and their proactivity. When reflecting on the subject one parent expressed "it's certainly a coping mechanism" (*ITC*, p.185: 9-21). Likewise another parent explained

> The only thing that turned it around for me was the fact that I knew I had to do things. And I put, I blanked it out, and put all my attention and focus in to, ok well I'm going to do my best, do all these things. So we just absolutely started focusing on doing those things. If I didn't do that, I'd probably be still sitting there totally depressed (*ITC*, p. 34: 21-24).

However, far from representing a denial of their grief, the proactive parents in this sample were among the most self-aware participants. They unreservedly articulated their emotional

responses to the diagnosis without any sense of suppression. They also openly expressed still experiencing feelings of grief intermittently. Many of these parents described working through the other coping mechanisms described in Stage #3 (such as withdrawing, releasing, seeking solidarity, and redefining encounters) before arriving to this task-centred, forward-looking, and positive mind-set. In addition, while desiring what was best for their child, the proactive parents in this sample exhibited a warm acceptance, enjoyment, and pride in their child. Thus, far from representing a suppression of grief or a maladaptive coping mechanism, the proactive parents in this sample were among the most well-adjusted participants.

It is important to acknowledge that the research did identify complications associated with undertaking roles. However, these complications (detailed in section 6.5.3 of the Findings Chapter) are nuanced and associated with the polarities of both disproportionate activity and disproportionate inactivity. For example, inordinate motivation is as problematic as indifferent lack of motivation. Likewise, excessive advocacy is as problematic as the passive lack of advocacy. While highlighting the dangers associated with proactivity neither Kurtzer-White and Luterman (2003) nor Young and Tattersall (2007) balance their concern with the opposite danger of parental inactivity, nor do they acknowledge the subsequent impact on the child's lack of development. This represents an imbalanced treatment of the challenges facing parents as they care for their child's needs.

7.6 The Parent-Baby Relationship.

The parent-baby relationship is of paramount importance. In particular, the parent's interaction with their baby in the aftermath of the diagnosis a crucial conceptualisation within this study. It is evident that countless authors question and/or investigate the impact of UNHS on maternal bonding, anxiety, and the developing parent-child relationship (Bess & Paradise,

1994; Paradise, 1999; Clemens et al, 2000; Manguson & Hergils, 1998; Weichbold et al, 2001; Hergils & Hergils, 2000; Van Der Ploeg et al, 2008; Vohr, 2008, Kurtzer-White & Luterman, 2003; Young & Tattersall, 2007; Fitzpatrick et al, 2007). Furthermore, the literature confirms that "the emotional climate of the parent-child relationship is a necessary context for the unfolding of child development in many domains" (Kurtzer-White & Luterman, 2003, p.232; Pressman et al, 1999; Jackson 2009). However, while these authors place a great significance upon the parent-child relationship, they do not specifically investigate the numerous ways in which the diagnosis practically impacts the parent-child interaction. A minority of authors discuss the potential for parents to become overprotective of their child (Luterman, 1999) or to become particularly proactive (Young and Tattersall, 2007). However, these reactions are identified in isolation and are not placed within a comprehensive investigation of the range of specific parental responses to their baby in the aftermath of the diagnosis.

The researcher's conceptualisation of the nine recurring reactions of parents to their baby (testing, initial perceptions, withdrawing, a lost celebration, new perspectives, proactivity, pride and affirmation, acceptance, enjoyment and humour) assembles the parental responses in a more comprehensive capacity. This is an important finding in enabling professionals to understand and support parent-child bonding. In addition the researcher's presentation of the two overarching principles imperative to the parent-child relationship (of acceptance and challenging the child to reach their potential) is a unique combination. Authors such as Kurtzer-White and Luterman stress the need for parents to "learn to accept their child" (2003, p. 235), and authors such as Yoshinaga-Itano (2003) correctly highlight the impact of parental involvement. However, the identification of these two principles simultaneously as traits that should complement and temper one another (rather than being in competition with one another), and infuse the parent-child relationship, is unique to this study. Again this is an important combination for professionals to model and encourage as they engage with families.

7.7 Overview: Contrasting Frameworks

While the majority of studies outlined in the Literature Review Chapter carefully and descriptively draw out themes of parental responses to an early diagnosis of hearing loss, the vast majority of articles do not assemble all the different components together to present a cohesive conceptual framework. This oversight is documented by a number of authors. Russ et al confirm that "studies examining parents perceptions of the screening and diagnostic process…tend to concentrate on one or two aspects of the experience" (2004, p.353). Likewise Hardonk et al observe that "research is often limited to the analysis of specific components of care trajectories, resulting in little being published on these trajectories as a whole" (2011a, p.306). In light of this scarcity, the four-stage model fashioned within the context of this study is a valuable conceptualisation. In addition to providing a structured and overarching framework, this model presents the parental experience of receiving and responding to an early diagnosis of hearing loss as a process, not a singular event. It also encapsulates a multi-dimensional perspective as it encompasses diverse responses and preferences, rather than suggesting a universal or homogenous experience.

Apart from the researcher's model, only one article in the Literature Review (authored by Hardonk et al, 2011a) addressed this conceptual gap and presented a framework encapsulating the parental experience of UNHS. Taking a theoretical perspective, Hardonk et al (2011a) proposed a five-trajectory framework which encapsulates the parental experience of receiving an early diagnosis. Significantly, this article was discovered after the researcher had already fashioned her conceptual framework of the four stages of parental coping. Both frameworks are displayed on the following page to ensure ease of comparison.

Figure 7.1 Congenitally Deaf Children's Care Trajectories in the Context of Universal Neonatal Hearing Screening (Hardonk et al, 2011a, p.310)

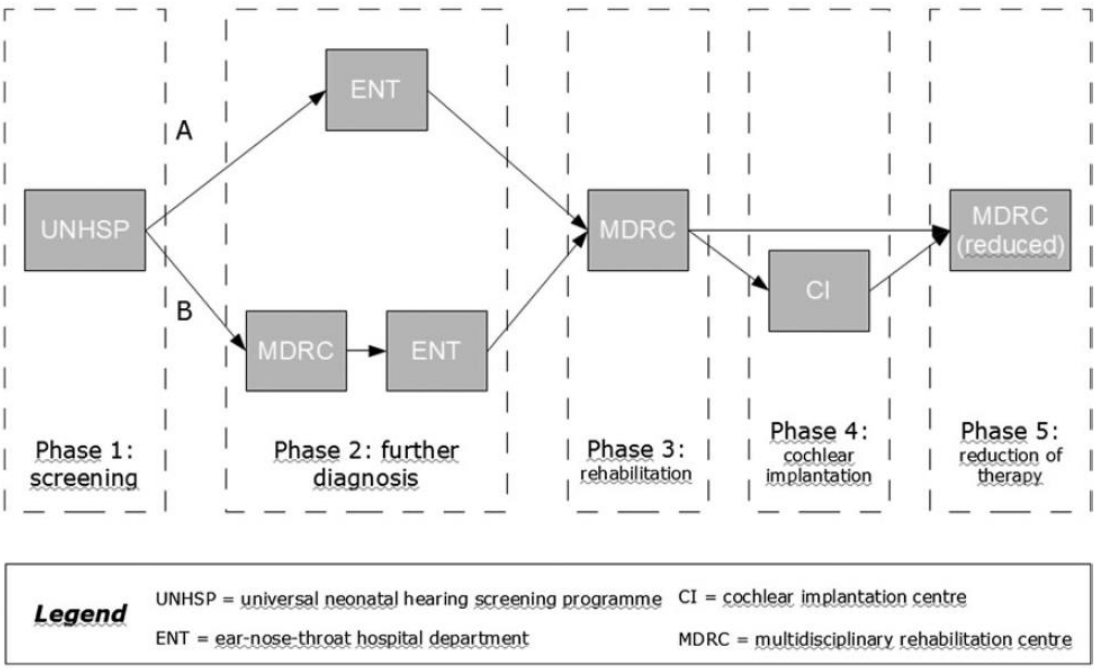
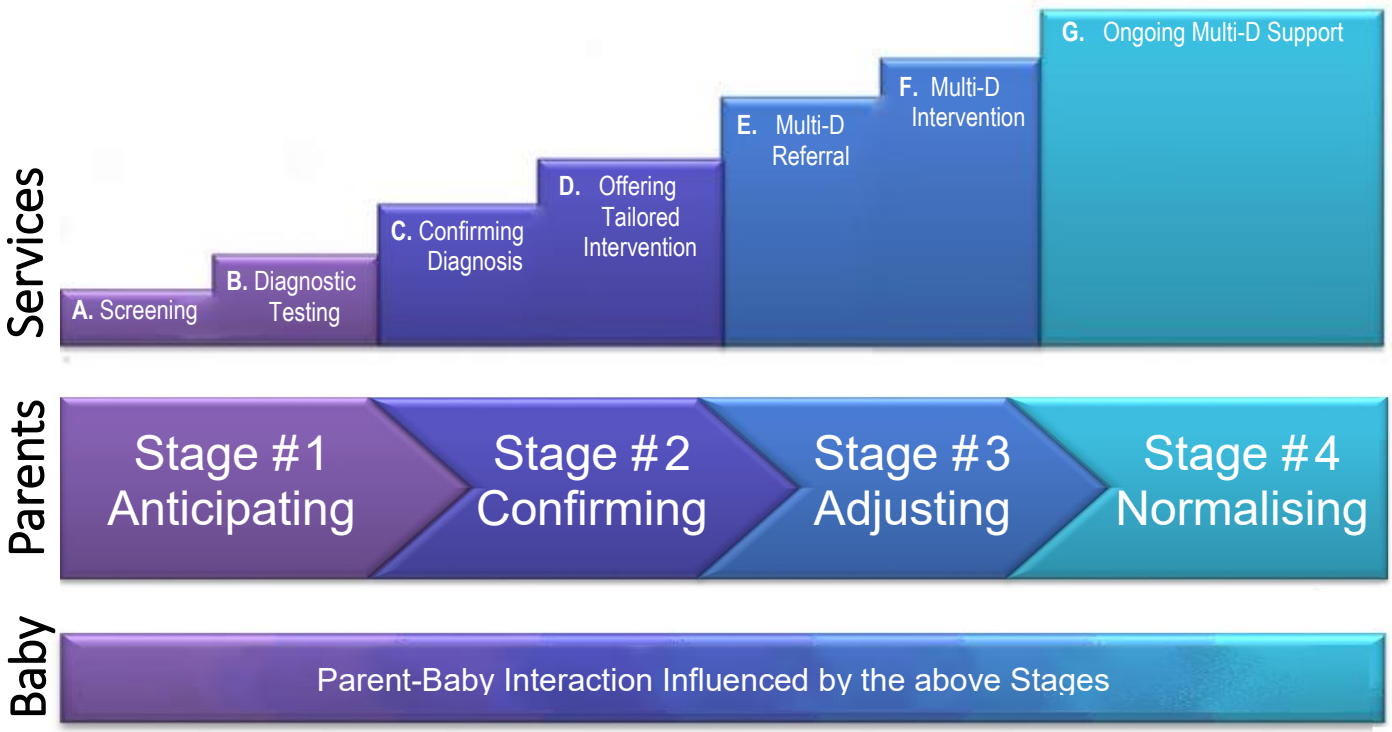


Figure 7.2 The Four Stages of Parental Coping (The Thesis of this Study)



The general sweep of both models is unmistakably similar. It is evident that the researcher's depiction of four overarching stages is comparable with Hardonk et al's five-trajectory framework (2011a) because both models are punctuated by the rhythm of service provision. Nevertheless, this similarity is remarkable given they were both created in isolation from one another, within the different social and cultural contexts of Belgium and Ireland, within different healthcare systems, and with different sampling and research tools. Hardonk et al's converging model (2011a) therefore confirms the dependability of this study and implicitly substantiates the researcher's framework of the four stages of the parent's journey.

However, despite their broad similarities, the detailed explanations of each stage/phase distinguishes the two models as disparate entities. In particular there are eight important differentiating factors distinguishing the two conceptualisations.

- Firstly, while the individual stages/phases of both trajectories are demarcated by similar intervals (screening, diagnosis, referral/rehabilitation), they are categorised differently. The researcher labels each stage in terms of the parents' overarching experience (e.g. Stage #1: Anticipating) in order to embody the parent-centred emphasis of her research. In contrast, Hardonk et al's (2011a) framework appears to focus more directly on service provision. This emphasis is reflected in the naming of each stage in terms of service delivery (e.g. Phase #1: Screening) as well as the inclusion of different arrows to indicate alternative care pathways. Thus, the two models embody contrasting emphases.
- Secondly, the authors' explanation of each stage/phase is demonstrably dissimilar in detail. For example, as parents await and receive a diagnosis, Hardonk et al (2011a) depict three emotional responses (disappointment, uncertainty, and lack of support). In contrast the researcher identified nine expressions of grief, as well as a further four alternative responses underlined by positivity and hope (detailed in section 6.3.2 and

6.3.3 of the Findings Chapter). In addition, she also examined the complexity of how parents manage these emotions, and considered the conflict of clashing coping mechanisms within families. Accordingly, while Hardonk et al's (2011a) conceptualisation is not necessarily contradictory, the two models are vastly different in depth.

- Thirdly, the breadth of concepts encapsulated within both models are also contrasting. The researcher's model encapsulates many themes which are absent from Hardonk et al's model (2011a). In particular, concepts such as the communication of the diagnosis to the parent, the characteristics of excellent professional practice, information needs, internet usage, the impact of family-to-family networking, the roles parents assume in their child's care, etc. are embedded within the researcher's model but absent from Hardonk et al's (2011a).
- Fourthly, the two models incorporate different levels of diversity and complexity with regard to alternative parental experiences, such as the predicament of a dual-diagnosis, families with a previous history of PCHI, positive responses to the diagnoses, etc. Hardonk et al's model portrays a generic parental experience without a consideration of these nuancing factors. In contrast, the researcher's model encompasses and accounts for these anomaly experiences.
- Fifthly, the consideration of the parent-child interaction receives different degrees of attention in both frameworks. Within the researcher's model the parent-child relationship receives a concentrated examination, with a careful analysis of the changing dynamics as families travel through the four stages. This consideration is absent from Hardonk et al's (2011a) trajectory.
- Sixthly, the subject of cochlear implantation is embedded differently within each model. While cochlear implantation is acknowledged by the researcher, she deliberately

precluded introducing it as a distinct stage within her model as it related to a minority of cases in her sample rather than representing a universal experience. From her limited data on the subject, the researcher concluded that the parental experience of cochlear implantation was complex and dense enough to merit a separate model of its own. The composition of this model[31] would necessitate an additional study with a concentrated emphasis. Significantly, Hardonk et al disagree with this assertion (2011a). They not only dealt with the subject of cochlear implantation more extensively within the framework of their trajectory, but incorporated it as a distinct phase, but "optional event", which can be bypassed (Hardonk et al, 2011a, p.310).

- Seventhly, the visual illustrations of the two models contrast with one another. The researcher's illustration encapsulates the three dimensions of service provision, parental experience, and the parent-child relationship each of which are stretched over four stages. Hardonk et al's illustration is more one-dimensional, depicting the five phases of service provision which encompass two alternative care-pathways (2011a).
- Finally, the accuracy of methodological classification undergirding each framework is disparate. Hardonk et al assert that their "analysis was based on [the] phenomenological approach" but they employ the language of Grounded Theory (GT), as they describe "open coding", themes which "emerged", and reaching the point of "saturation" (2011a, p. 308, 309). They also undertake data collection in waves, with intermittent analysis (Hardonk et al, 2011a). These methodological details represent hallmarks of GT. In addition, Hardonk et al describe compiling a coding tree with "higher-level codes", which is indicative of a GT coding structure (2011a, p.309). Thus, their methodological

[31] The researcher conjectured that this alternative model (of parental coping with paediatric cochlear implantation) could be characterised by six stages: 1) Anticipation of Eligibility, 2) Confirmation of Eligibility, 3) Waiting for Surgery, 4) Surgery, 5) Adjustment, 6) Normalisation. Each of these stages appear to be multi-dimensional with manifold sub-categorisations. These conjectured stages of cochlear implantation are preliminary and necessitate a further study for refinement and validation. This study should be undertaken with a selective recruitment strategy targeting a more specific cohort of parents

classification of phenomenology is dubious. In contrast, the researcher's methodological demarcation of a soft Straussian GT (with Constructivist and Classic influences) is exhaustively defined and defended.

These eight factors distinguish these two frameworks as distinctive entities. However, while they differ in terms of depth, breath, comprehensiveness, complexity, and accuracy, they are not incongruent frameworks as they are both reinforced by a similar overarching structure. Significantly, this combination of distinctiveness and congruence implicitly confirms both the validity and originality of this study.

7.8 Conclusion: The Eye of the Beholder

In drawing this Discussion Chapter to a close, it is important to acknowledge the implicit influence of the analyst as she conducts the analysis. The critical realist position adopted in this study recognises that the researcher's influence pervades the research process from design, to execution, to conclusion (Kuhn, 1970). In particular, this researcher's background as a social worker was particularly significant. When fashioning the research design, the researcher deliberately included the *Samaritans' listening wheel* as a point of reference for conducting interviews. Her personal experience of training in this tool was immensely significant in shaping her approach to supporting individuals in distress. While interviewing, the listening wheel equipped the researcher to draw out the stories of participants while carefully offering affirmation, compassion, and support. In writing up the findings, the researcher's social work training was evident in her caution towards preserving the confidentiality of participants which led her to create a referencing system that safeguarded as much anonymity as possible. Having previously worked with individuals in distress the researcher was empathetically engaged with

the experiences and concerns of participants. The researcher was also cognisant of the need to affirm the good and acknowledge the positive impact of parents' commitment to their children. As a social worker, with experience of multi-disciplinary teams, the researcher was convinced by the participants' grievances and recommendations for better interdisciplinary communication and collaboration as well as the need for a holistic approach. Having worked in flawed structures herself, the researcher also understood the legitimacy of the participant's frustrations with structural deficiencies. The researcher's background also attuned her to issues of parental withdrawal, a point which she inquired about in interviews. This inquiry precipitated the identification that withdrawal from all forms of communication (speech and sign) would represent a serious issue of child neglect. The researcher's subsequent recommendations outlined in the following chapter were influenced by the values of striving for best practice, which led her to be specific, direct, and ambitious in seeking genuine and positive change. Thus, the background of the researcher was clearly an important influence in numerous ways throughout this research endeavour.

8. Conclusion

8.1 Introduction

This study represents more than an academic endeavour. Since the inception of the study, there has been an underlying aspiration to apply this research to the UNHS programme in Ireland, and fashion recommendations for improvement. Participants who engaged in this study were motivated by the same objective and disclosed deeply personal experiences and reflections with the hope of improving the system for other families. These participants made many specific recommendations which were particularly astute given their personal experience. It is fitting therefore to conclude this study with a vision for change.

The recommendations outlined within this chapter are classified under the four categories of service structure, professional practice, social support, and use of data. The process of fashioning these proposed changes necessitated a careful consideration of the NARG Report, which formed the context of this study (2011). However, rather than repeating the proposals outlined in the NARG Report, the researcher sought to develop them within the context of this research. Significantly, the subsequent recommendations outlined in this chapter are not intended to undermine the important achievements of the UNHS programme in Ireland, or to criticise the many exemplary professionals within this domain, but to offer a hopeful vision for future progression.

8.2 Recommendations for Improving the Structure of Services

The coordination of services impacts parental coping. This theme was strongly evident within the Findings Chapter as parents' experience of adjusting to their child's diagnosis was hindered or helped by the organisation of early intervention services that surrounded them (see section 6.4.1 a). A coordinated multi-disciplinary system, constituted by clear referral pathways, timely interventions, ongoing professional collaboration, and holistic care, engendered a tremendous sense of comfort for families. In contrast a poorly coordinated system

of services, composed of disparate services with little interaction with one another, constituted by ambiguous care pathways, and long delays, caused acute distress to families. It is crucial to acknowledge that the present coordination of UNHS services in Ireland is undoubtedly more closely aligned with the former than the latter. Nevertheless, there are still important improvements to be made. In particular, the need to formalise the interconnection of multi-disciplinary services to ensure they work in conjunction, rather than in isolation from one another, is imperative. This assertion is substantiated by the participant check which documented that 100% of parents either agreed (86%) or strongly agreed (14%) with the recommendation for more holistic organisation of services (*PCS*, q.13). In addition, the NARG Report which strongly asserted the need for a more "cohesive approach" in "the provision of services", pinpointing the critical need for the" integration" of services and "clear channels of communication" between "disciplines and agencies" (2011, p.60, 63). It is not appropriate to expect parents to mediate this collaboration and relay technical information from one service to another. **Consequently[32], the researcher upholds the findings of the NARG Report and strongly recommends that formal protocols urgently need to be created to improve the connectivity of services, clarify the channels of communication, and formalise multi-disciplinary collaboration. In particular, the researcher recommends that these protocols should address:**

- **Communication and information-sharing**: It is crucial to formalise the ongoing dissemination of results and reports between disciplines and agencies. This information should be confidentially circulated to the entire multi-disciplinary team (working with the family) rather than confined to one particular service. This protocol for disseminating information would enable services to work together,

[32] As each recommendation is embedded within explanatory text, the specific call for action is highlighted in bold text, and subsequent bullet points, to ensure clarity and ease of retrieval.

building upon each other's work, rather than operating in isolation from one another. Compliance with this protocol should be monitored. An online database may be a helpful medium to facilitate this sharing of information in an efficient and inclusive manner.

- **Clarification on issues of confidentiality**: Parents should be fully aware that information is circulated between the team rather than confined to a service. Their permission for this dissemination should be sought for this from the outset and need not be repeated for every report. All reports and correspondence should also be forwarded to parents to ensure transparency and inclusiveness.
- **Clarification regarding the inclusion of services:** The resources of community charities were not consistently offered to parents or always utilised by early intervention services to their fullest capacity. There should be consensus as to what services are incorporated within the multi-disciplinary team and a consistent inclusion of them.
- **Care-Plan:** An individual care-plan (named an "Individual Management Plan" in the NARG Report) should be created for every child, clarifying their specific needs, outlining goals, and identifying the services which are required to support them. This care-plan should be reviewed annually by the multi-disciplinary team in conjunction with the family in order to evaluate the child's progress, the sufficiency of service provision, and to provide a forum for forward planning.
- **Multi-disciplinary team meetings**: Joint meetings between agencies and professionals should be regular occurrences and a matter of priority. This is crucial to ensure that professionals across disciplines operate as a team, rather than in isolation from one another, and have a regular forum to collaborate and address concerns. These team meetings could also present opportunities to discuss

particularly complex cases and to enable joint decisions. In these particular instances, the case-led meetings should be inclusive to all professionals working in conjunction with the family and the parents of the child should also be invited to attend.

- **National implementation**: These protocols need to be implemented nationally to ensure geographical consistency. These policies should also include a consensus of care-pathways and appropriate timeframes which should be monitored across all geographic regions. This is corroborated within the NARG Report which stresses that "there is the need for a national standardised service ensuring equity across the regions as well as standardised operational policies and procedures to ensure consistency" (NARG, 2011, p. 61).
- **Community clinical awareness**: It is crucial to provide sufficient information and education to community health practitioners (such as GPs and Public Health Nurses) with regards to UNHS. This is important to, firstly, ensure they provide appropriate guidance and support to families during antenatal appointments. False reassurance or inaccurate advice can be very harmful. Secondly, in the case of a child who received a false-positive result or in the predicament of an acquired hearing loss, it is essential that community health practitioners can recognise the subtle signs of hearing loss in young children and make the appropriate referrals. Thus the holistic care of the child extends to community practitioners.

These recommendations are critical to forge the ongoing collaboration between multi-disciplinary services and solidify a cohesive team approach to the child's care.

In addressing these issues of connectivity and communication between services, the NARG Report (2011) recommended the creation of the new role of a *link worker*. However, while implying the link worker would bring greater cohesion to the multi-disciplinary team,

the NARG Report did not specify their exact role. Consequently, **while unreservedly endorsing this recommendation for the new position of a link worker, the researcher recommends that this position should encompass two overarching roles:**

- **Multi-disciplinary coordinator:** Firstly, the link worker should oversee the coordination of the UNHS programme, taking responsibility to ensure a more collaborative multi-disciplinary team approach to working with families. He or she should supervise the ongoing implementation of formal procedures particularly regarding the dissemination of reports and the organisation of multi-disciplinary team meetings. The link worker should also ensure the creation of an individual care-plan for each child with multi-disciplinary and family input and also organise the subsequent annual reviews to monitor progress. In addition, the link worker could also be responsible for the establishment of a Children's Hearing Services Working Groups[33] (CHSWGs) as recommended in the NARG Report in order to provide an ongoing evaluation of service proficiency.
- **Family advocate**: In addition to their role of coordination, the link worker should also work directly with families. He or she should engage directly with parents from the latter half of Stage #1 onwards to ensure the continuity of care for families throughout their journey. During Stage #2, the link worker could be present in the diagnostic appointment to provide emotional support or, alternatively, could follow up with parents very quickly after the diagnosis. With this level of direct engagement during periods of acute vulnerability, the link worker should have adept counselling skills and be trained in supporting parents during distress. The link

[33] The NARG Report clarifies that the purpose of this recommended group is to "monitor service performance, to encourage and support innovation and improvement, and to involve users in planning, provision and operational changes to services" (2011, p. 17). Furthermore, the NARG Report stipulates that this group should be comprised of "multidisciplinary and multiagency membership, and include significant representation from parents of children with hearing impairment" (2011, p. 17).

> worker should also be a consistent point of contact for families during Stages #3 and #4 of their journey, enabling parents to navigate the system of services, empowering them to undertake their roles, and also helping families overcome any problems they are encountering. In addition the link worker should have the capacity to work with families through additional circumstantial concerns (such as total withdrawal from all services, social issues, etc.).

The professional background of the link worker should therefore encompass both proficient coordination skills as well as adept counselling skills. Given these two overarching skill sets, a qualified social worker (with expertise in hearing loss) may be in the best position to undertake this role. It is crucial to stress that this role should not detract from the importance of other professions (such as a visiting teacher or a charity social worker). Rather, the link worker should work in conjunction with these important disciplines.

The participants in this study emphasised four further recommendations relating to the structure of the UNHS programme. Firstly, the identification of appropriate environments for families was an important need raised in interviews. Parents of an older child with hearing loss highlighted that the initial new-born hearing screening is conducted in an open, public maternity ward. Due to their heightened level of awareness, these particular parents interpreted the initial screening of their new-born baby in a diagnostic capacity (despite any reassurance to the contrary) and felt upset by the lack of privacy afforded to them as they received and responded to the failed screen. (This was not the case for parents without this family history, who did not attribute as much significance to the initial hearing screens.) Special sensitivity and privacy should therefore be afforded when screening babies with an immediate family history of hearing loss. In addition, given the demographic of all families within the UNHS system, it is essential to have sufficient space in waiting rooms with facilities to enable parents

to feed and change infants. These practical considerations are crucial. Furthermore, as parents are often nervous and vulnerable while attending appointments, both the waiting and clinical rooms should be comfortable, warm, and inviting, engendering ease rather than discomfort. Consequently, the **researcher echoes the recommendation of the NARG Report that it is essential to "provide a family-friendly environment with privacy" at all stages of the child's care, from screening, to diagnosis, to intervention (NARG, 2011, p.81).**

Secondly, the necessity to adequately resource services was also highlighted by parents in this sample, who were cognisant of the pressure and strain professionals were under as they often struggled to offer timely appointments. Both this current study, and the NARG Report (2011) concur that it is only possible to achieve a high quality of services with appropriate resources and staff. In particular, the NARG Report (2011) specifies that the staffing levels should be "more than doubled" (p.18) and stipulates the necessity to recruit the following:

- "An additional 23.5 assistant audiologists
- An increase of 21.1 WTE graduate level audiology staff
- An increase of 38.9 WTE postgraduate level audiology staff" (NARG, 2011, p.18)

While the adequate staffing of audiology services is an essential and legitimate need, so too is the imperative to recruit other essential professionals (such as visiting teachers of the deaf) whose services are also under resourced and overstretched. The NARG Report corroborates this assertion with the stipulation that the current visiting teacher service "is overstretched" and "an increase in staff resources is urgently required to support the newborn hearing screening initiative" (NARG, 2011, p. 19-20). Consequently, **the researcher recommends the recruitment of multi-disciplinary staff, in accordance with the guidelines of the NARG Report, to sufficiently resource the UNHS programme in Ireland.**

Thirdly, the issue of opening hours was raised in interviews, with the identification that a 9am-5pm service can exclude a working parent. This represents a logistical difficulty in

attendance. One participant highlighted that in the case of a two-parent family, this predicament can place inordinate pressure on the parent who attends the appointments to retain complex information and relay it to their spouse/partner later. This can incur great frustration and stress for both parents. This issue of opening hours is also highlighted within the NARG Report, with the recommendation that "audiology departments" should "introduce flexible working hours for the benefit of users of the service in particular working patients and/or school age children" (NARG, 2011, p. 17). However, this need extends to all services, not just audiology, and as a consequence **the researcher recommends, where possible and appropriate, the structuring of services to accommodate and include working parents.** Even the availability of each service one Saturday morning per month or one evening per week (with time taken back in lieu) may be sufficient to meet this need.

Finally, the availability of written information for parents at the point of diagnosis was a point of ambiguity within this study. The NARG Report also addresses this issue, asserting:

> We recommend that services provide full and comprehensive information to patients/carers in a variety of accessible formats, including information on services provided by the voluntary and private sectors. (NARG, 2011, p. 17).

However, there seemed to be confusion as to whether this was implemented or not. An Irish based charity organisation have previously worked in conjunction with the HSE to create a comprehensive booklet for parents collating information relating to hearing loss. However none of the parents in this sample mentioned receiving it. Additionally, as a separate project, the charity also gathered a group of parents together to create a pamphlet, specific to UNHS in Ireland, which succinctly collated all the important information (relating to an early diagnosis of hearing loss) into one source. However, the consistent distribution and availability of this pamphlet was also ambiguous. Parents seemed to receive different resources from different professionals and one of the criticisms a parent voiced was that the collection of leaflets she received from various appointments had no sense of order or cohesion. The dissemination of

information therefore needs to be clarified, particularly as this represents one of the most significant needs parents experience in the wake of an unexpected diagnosis. In addition, the language employed in this information should be particularly sensitive as parents in this sample discussed feeling upset by labels such as “disability” or “deaf”, particularly in the early stages of their journey. **Consequently, the researcher recommends a consistent availability of the applicable, appropriate, comprehensive, and collated information to all parents of newly diagnosed infants across the HSE in Ireland.**

8.3 Recommendations for Improving Professional Practice

Before launching into the forthcoming recommendations regarding professional practice, it is imperative to firstly acknowledge the many exemplary staff presently working in the domain of infant hearing loss in Ireland. Parents within this study sample consistently commended the significance of many key professionals (across a variety of disciplines) who impacted their journey. Parents highlighted the excellent expertise of these professionals, emphasising their compassionate concern and conscientious commitment. Parents also described the sense of encouragement and empowerment that these professionals impart to families during appointments. Consequently, the following recommendations do not represent a criticism of these admirable individuals but, rather, an appeal to all professionals in the field of infant hearing loss to value and exemplify the same standard of care. There are two broad categorisations within this high calling.

Firstly, particular care needs to be taken when imparting important or distressing news to parents (particularly a diagnosis). This is applicable not only to audiologists but to other clinical professionals such as paediatricians and ENTs. Many of the principles are also germane to professionals such as a visiting teachers, speech and language therapists, or social workers,

as they engage with families during times of acute vulnerability. To ensure the utmost support and sensitivity, **the researcher strongly recommends that professionals should prioritise:**

- **Preparation**: In the lead up to the diagnosis, the clinician has a dual obligation to cultivate anticipation but curtail anxiety. They need to sensitively prepare parents to receive a diagnosis by creating a sense of context and expectancy. However, they also need to ease anxiety, providing reassurance and support to parents (see section 6.2.3 of the Findings Chapter).
- **Clear and compassionate communication:** In giving a diagnosis or critical news the professional has a dual role. Firstly, they have a responsibility to impart information as clearly as possibly. The professional needs to be adept at explaining complex information in an understandable language while employing their discretion to judge the appropriate manner of delivery, detail of delivery, and the apposite level of hope to offer (see sections 6.3.1). Secondly, the professional has an ethical obligation to support parents as they emotionally respond to the implications of the news they deliver. This should be seen as a crucial aspect of their role and all professionals should receive training (outlined in section 8.5) to enable them to undertake this challenging task.
- **Time and accessibility:** It is essential for the professional to allow ample time for these important appointments, creating the space to hear parents' questions and concerns and respond appropriately. It is also imperative for the professional to give parents their contact information, with the genuine offer of availability.
- **Sensitivity to issues of retention:** It is essential for the professional giving any kind of diagnosis or shocking news to be sensitive to the lack of parental retention in these appointments. Although the information may be imparted clearly, parents "are generally not psychologically prepared to process it" (Luterman, 1997). Professionals should therefore reassure all families that they will ring them the following day to

answer any questions or concerns that may have arisen. It may be helpful to even arrange a particular time to ring parents in order to ensure availability and to safeguard against parents anxiously awaiting a phone call. Upon making this commitment, it is essential for professionals to follow through with it consistently.

- **The provision of written reports:** Across all disciplines, and at all stages of the parents' journey, a radical improvement would be to give parents a written report at the end of any important appointment. This would support parents to relay the information to a spouse/partner/extended family, thereby reducing the stress of retention and subsequent explanations.
- **Follow on intervention:** As families leave diagnostic appointments, it is critical for professionals to provide them with three things. Firstly, they need to impart written information relating to their child's diagnosis to parents. This information should also explain interventions, supports, care-pathways, etc., in an accessible format. Secondly, the professional needs to provide timely follow-on intervention within their own services, where appropriate, letting the family know when their next appointment will be. Thirdly, the professional need to reassure families that they will make the appropriate referrals on their behalf, ensuring they are linked in with multi-disciplinary services and supports. It is essential for the professional (rather than the parent) to coordinate this referral process and subsequent services should make a concerted effort to link in with the family as soon as possible, where appropriate.
- **Seeking supervision:** Given the emotionally-intensive role of supporting families through acute vulnerability and distress, it should be compulsory for professionals to have regular supervision sessions with a counsellor. This would provide professionals with an opportunity to debrief, process their experiences, reflect on difficult encounters, develop their self-awareness, and manage their demanding role. Supervision would also

guard against the burnout and subsequent turnover of staff, thereby providing families with more continuity.

These recommendations are consistent with the NARG Report (2011). Although the Report refrains from providing the same depth of detail, it nevertheless affirms that receiving a diagnosis "is a key moment in the parent's journey", emphasising that it needs to be "managed sensitively by someone with the appropriate training" (NARG, 2011, p.60). Significantly, while the above recommendations are largely centred upon the diagnostic phase of the parents' journey, it was evident from this research that a number of additional principles should govern the professionals' ongoing interaction with families. Consequently, **the researcher recommends that professionals should actively seek to emanate the principles of:**

- **Prior preparation**: It is essential for professionals to prepare in advance for appointments to create a sense of continuity. They should read the file in advance, be generally familiar with the case, aware of the diagnosis, cognisant of any current issues, address the parent and child by the correct name, and build on the previous appointment. This is critical to establish a family's sense of trust and confidence in the service. This recommendation is particularly important if there has been a long time-lapse between appointments, or where there is a rotation of professionals within one service.
- **Professional collaboration**: As well as requiring a formal protocol, it is also the responsibility of the individual professional to actively collaborate with colleagues from other disciplines and agencies. As well as the initiation of informal phone calls, they should circulate reports and share information with the parents' knowledge. This collaborative approach is particularly important when working with a complex case or dealing with concerns. In addition to substantiating a more cohesive multi-disciplinary

team approach, this professional collaboration would consolidate a more holistic perspective of the child and their needs, and dismantle a singular, one-dimensional vision of individual services.

- **Parent collaboration**: As families adjust to the diagnosis it is important that professionals engage in an increasingly collaborative capacity with parents, where appropriate. This includes jointly working for the child's benefit and placing a high value on the parents' perspective, role, and input. Parents in this sample appreciated this kind of collaborative relationship with their professional, experiencing it as empowering and dignifying.
- **Internal administration**: It is critical for professionals to manage their internal filing structure effectively. There should be a system in place to ensure the consistent and timely dissemination of internal reports to parents and relevant services. Within patient files the key information needs to be easily accessible. Notes from the previous appointment must be available. Both internal and external reports need to be up to date and filed chronologically (from most recent to older). Particularly where there is a rotation of professionals within one service or a long time-lapse between appointments this would ensure that the key information is easily accessible, thereby reducing the need to ask parents to relay this information. It would also enable the professional to build upon the previous appointment rather than repeating work.
- **Raising concerns:** If concerns arise in relation to a child (e.g. multiple complications, withdrawal from services, or social issues) it is crucial for the professional to raise this with the proposed link worker and within the wider multi-disciplinary team. The previous recommendation for a multi-disciplinary team meeting could be a particularly helpful forum for addressing and working through these concerns in a cohesive capacity and create a joint care-plan for the child. The link worker could initiate this meeting,

and oversee the implementation of this care-plan. In the case of social concerns, they could also link in with a charity social worker (specialising in hearing loss) in seeking a positive resolution.

- **Training:** It is only possible for professionals to reach and maintain these high standards of care with ongoing training, specific to the unique dynamics of UNHS. In particular, imparting counselling skills should be prioritised as many of the professional have not received adequate training within their vocational courses to teach them how to support families through acute vulnerability. This should be funded as a matter of priority. Furthermore, joint training would create a medium for inter-agency introductions, enhance inter-disciplinary collaboration, and promote consistent standards of care across geographical regions.

8.4 Recommendations Regarding Social Support

One of the most vital sources of support many participants reinforced in interviews was the need for family-to-family contact. The empathy, encouragement, solidarity, and advice of other parents in the same predicament was instrumental in enabling many participants to cope. In addition, meeting an older child (or adult) with a hearing loss, was often a turning point for families which engendered tremendous hopefulness. This finding is corroborated within the literature, as Luterman and Kurtzer-White confirm that parents' "predominant need during the identification process was contact with other parents" (Luterman & Kurtzer-White, 1999, p.17). In addition, the importance of parent-to-parent contact is also substantiated by the NARG Report which identifies "the need for a network that would allow parents and children to link and support each other" (NARG, 2011, p. 61). Consequently, **the researcher recommends that the opportunity to meet other families should be consistently offered to every parent. To facilitate this it is important to consider:**

- **Multiplicity**: It may be most helpful to offer parents a number of forums for family-to-family networking. This could include the option of a telephone conversation with another parent, meeting a parent in person, parent-toddler groups, parent information nights, family fun days etc. By offering a number of alternatives, the parent may be able to engage in whatever manner they feel most comfortable.
- **Inter-agency collaboration:** Select parents and representatives from the multi-disciplinary team (audiology, visiting teacher, community charities etc.) should have a specific meeting to jointly decide the most effective approach to practically facilitating family-to-family contact. It is crucial that they pay careful attention to the cautions outlined in section 6.4.2 d of the Findings Chapter of this study.
- **The uniqueness of a dual-diagnosis:** In the case of dual-diagnosis (particularly when hearing loss is the secondary need), it is more helpful to parents to meet other families in the same circumstance. Every effort should be made to facilitate this important connection.

As well as the significance of family-to-family support, it has become clear throughout this research that the wider social context is a crucial factor in parent's adjustment to their child's hearing loss. The lack of exposure to Irish Sign Language (ISL), the lack of encounters with Deaf role-models (speaking, singing, and bi-lingual), and the lack of awareness of Deaf culture, is indicative of Irish society at large. This is a significant problem for parents during Stage #1 and #2 of their journey because this vacuum often compounds their sense of fear, worry, anxiety, and distress as they receive a diagnosis. It also creates misconceptions about hearing loss which can cause unnecessary stress. Significantly, this lack of social awareness is also a problem for parents during Stage #3 and #4 of their journey because they are faced with

the burden of raising awareness within their surrounding community by educating their extended friends, family, and acquaintances who typically have no understanding of hearing loss. During this never-ending task many parents feel frustrated by the misunderstanding and ignorance they encounter.

To address both these predicaments there needs to be more social education. Rather than restricting the trifold ambition of the cultural-linguistic model of hearing loss (promoting sign language, Deaf-culture, and Deaf role models) to early-intervention services, it should be readily available at a general social level to precipitate awareness and dispel misconceptions. This could create a frame of reference for parents prior to diagnosis and also encourage a general community awareness. If it were successful, would the fear of the unknown be greatly reduced as families receive a diagnosis? Would families experience more social support as they care for their child? Would children with hearing loss grow up in a more inclusive climate?

To achieve this end, **the researcher recommends that *Deaf Studies* should be made available as a Junior and Leaving Certificate subject in Ireland. This course would encompass the two-fold focus of:**

- **Sign Language**: Deaf Studies should encompass learning Irish Sign Language (ISL) to an accredited and proficient level, challenging students to reach a reasonable level of fluency.
- **Cultural Awareness**: The course should also include a study of Deaf culture and pertaining issues which would encompass studying Deaf literature and history, examining the debates of different philosophical/political positions (bilingual, signing, speaking), and having exposure to Deaf role models who represent each of these alternative positions.

This recommendation is crucial for four reasons. Firstly, offering Deaf Studies as a Leaving Certificate subject would ensure widespread availability and lift many of the stigma and myths associated with hearing loss. Within the context of this study this would benefit parents faced with an unexpected diagnosis and also raise positive awareness for deaf children growing up in Ireland. Secondly, ISL is recognised by linguists as a comprehensive language (akin to German, Spanish, Italian, etc.) and should be treated as such in the Irish mainstream education system. If it can be accredited to a degree level in Trinity College Dublin, it can be accredited to Leaving Certificate level in secondary schools. Thirdly, ISL is a native language of Ireland, and should be protected as part of our national heritage. Fourthly, according to the 2011 Irish census, 92,060 people within Ireland (representing 2% of the population) were either deaf or had a "hearing related disability" (Central Statistics Office, 2012, p.1). While this certainly encompasses a broad spectrum of individuals, the diversity of people with hearing loss nevertheless represent an important minority group in Ireland. ISL and Deaf awareness should be available as a Leaving Certificate subject as a means of social inclusion and equality, particularly for those who rely on ISL as a primary language. Each of these considerations corroborate the researcher's recommendation[34] that *Deaf Studies* should be available as a (Junior and) Leaving Certificate subject in Ireland.

[34] This recommendation is strongly corroborated by Matthews (2011). However, she takes the argument a step further. Matthews highlights that within the Irish education system deaf/hard of hearing students are exempt from taking Irish as a Leaving Certificate language (2011). This exemption inadvertently precludes these students from entry into any primary school teacher-training colleges in Ireland, as honours Leaving Certificate Irish is a fundamental requirement (Matthews, 2011, p. 1). As a consequence of this "barrier" there is no available "avenue" for deaf/hard of hearing students to pursue primary school training and subsequently to "work in the field" of deaf education (Matthews, 2011, p. 1). Matthews stresses that this has resulted in a scarcity of deaf/hard of hearing teachers, which is "particularly unsatisfactory", not only as a point of discrimination but also in removing Deaf role-models from Deaf education in particular (2011, p. 1). To combat this predicament, Matthews advocates for the creation of an ISL entry route into teacher training colleges in Ireland which should have an ISL, rather than an Irish language, prerequisite (Matthews, 2011). Matthews proposes "the main aim of such a programme is to provide teachers to work in the Deaf education sector" (2011, p.1). Consequently, the need for Deaf Studies or ISL as a Junior and Leaving Certificate subject in Ireland is crucial as a means of facilitating alternative entry requirements for university courses and subsequently enabling vocational inclusion and role modelling.

8.5 Recommendations for Using this Data

In placing a high value on research, Strauss and Corbin confer a high responsibility on the researcher. They insisted that the researcher has an ethical responsibility to make their findings easily available, not for her own acclaim, but to contribute to the body of knowledge on the subject and affect positive change. In addition, 100% of parents within the participant check either agreed (57%) or strongly agreed (43%) that "professionals should be made aware of this model" (*PCS*, q.14). **The researcher therefore recommends that the research** findings **should be disseminated upon completion of this study to ensure widespread accessibility. This dissemination could be undertaken in a number of formats including:**

- **Publications:** The researcher should make every effort to publish the findings and recommendations of this study in a peer-reviewed journal that is preferably open-access (to ensure the utmost availability of the study).
- **Follow-up contact:** These publications should be posted to participants who engaged in this study and requested to see the findings [35]. In addition these publications should also be dispatched to authorities within the UNHS programme in Ireland for their serious consideration. Furthermore, in April 2014 the researcher presented the preliminary findings of this study in a poster presentation at the *Early Detection of Hearing and Intervention* conference in the USA (see Appendix F). A number of attendees working within the domain of UNHS internationally gave their contact information to the researcher requesting that further publications be emailed to them. The researcher should follow through on her acquiescence with this request.

[35] As a consequence of the participant check, a DVD of the research findings has already been posted to parents, which has ensured they have been among the first to see the findings of this study.

- **Further Research:** The research findings should be developed beyond the confines of this study. Having fashioned the four-stage model through the medium of qualitative analysis, it would be beneficial to engage in further research to quantitatively corroborate the model. This further research would necessitate a different methodology, research design, and sample, as its purpose would be to validate (rather than generate) a conceptualisation. In addition, it would be pertinent to engage in further qualitative research to study the parental experience of cochlear implantation in Ireland, with a view to fashioning an analogous model depicting the stages of parental coping.
- **Transferability:** While the present study specifically concentrated on the subject of parental coping with infant hearing loss, the findings have the potential to be applied more generally to the wider healthcare domains of "receiving bad news", or "parental coping with unexpected diagnosis", or "best-practice principles". This application should be pursued to ensure that the findings of this present study are utilised to their fullest potential.
- **Presentations:** Following completion of this study, these findings and recommendations could be presented to parents and/or professionals working in conjunction with UNHS in Ireland. This presentation could be delivered at either a conference or an organised event. In the case of the latter, the invitations to attend should ideally be inclusive to all agencies, such as the HSE, Department of Education, and charity organisations, as well as to any interested parents.
- **Offering resources:** Existing links with Charities and HSE should be followed up to explore how this present study might be useful to them in terms of their own resources and internal training. One Irish Charity in particular expressed interest in utilising this research to create further publications for parents.

- **Training:** This study could be used to create a *Continuous Professional Development* (CPD) programme specifically for professionals working within the domain of UNHS. This programme would encompass presenting the model of this study, with an in-depth exploration of how to support parents during each of the four unique stages of their journey. It should also concentrate on the professionals' role in supporting parent-baby bonding. Furthermore, this suggested programme could also be adapted into a university course, with the objective of training students how to support families through acute vulnerability. The availability of this course would combat Luterman and Kurtzer-White's criticism of the lack of counselling training that clinical professions receive (1999).

8.6 Conclusion: A Call to Action

In drawing this study to a close, it is critical to ensure that the research findings do not sit idly on a shelf, gathering dust in the archives of academia. The vision for continuing to improve the UNHS programme in Ireland, is not only the objective of this study, but also the express desire of the participants who engaged in this research. The recommendations embedded within this concluding chapter are therefore not empty proposals, but serious calls to action. They confer a double obligation, firstly on the researcher to disseminate the findings, and secondly, on the readers to seriously consider their appropriate implementation. We are not passive agents in the process of change. In the words of Gandhi, "the future is determined by what we do in the present" (cited in Hutchinson, 1996, p.57).

9. Epilogue

Strauss and Corbin affirm that research is not impervious to the researcher (Strauss & Corbin, 1994; 1998). Having completed this study, I have come to realise that the opposite is also true, the researcher is affected by the research. The process of studying the parents' journey of responding to infant hearing loss, has been silently undergirded by my own personal journey. As I reflect on the course of the past three years, I am struck by the important milestones that defined my own voyage of undertaking this study.

I remember my first phone call with my supervisor Dr Robert Fourie in August 2012. I was working as a social worker at the time, and answered my phone expecting a work-related conversation. I was surprised to hear the voice of a lecturer from UCC at the other end of the phone, and genuinely overwhelmed when he offered me the opportunity to undertake this study. I scarcely knew how to respond. I had previously convinced myself that a Department of Speech and Hearing Sciences would never be interested in an application from a social worker. I had resigned myself to the reality that in addition to this improbability, my request to spend a portion of the study abroad would surely disqualify me from any serious consideration. With this logical reasoning I had fully prepared myself to receive a rejection letter. When Dr Fourie unexpectedly rang, and dispelled all these preconceptions, I sat at my desk flabbergasted. I was unable to reign in my racing thoughts or to concentrate on work. I was overcome with a gratitude that I scarcely dared to believe. Could this really be true? I felt blessed beyond measure. This sense of blessing, of receiving this opportunity as an unexpected gift, has permeated this study from beginning to end.

I remember my first meeting with Dr Fourie (who soon told me to call him Robert). I recall being awed by his erudite presence, and lost for words when he asked me what methodology I'd employed for my previous research endeavours. I pieced together a feeble answer, which disclosed more ignorance than knowledge. He listened graciously, and without incurring any embarrassment, explained why the philosophy of research is important. He suggested it should constitute a third of this study. In hindsight I do not know if Robert expected me to take his guidance literally, but I certainly did so. This first conversation sparked my quest into the unknown territory of epistemology. Initially, I felt so lost as I struggled to find my way through the labyrinth of philosophical thought. It seemed so incomprehensible to me. However, over time, a newfound understanding began to dawn. As confusion gradually gave way to clarity, I began to see the beauty of the concepts that had once overwhelmed me. I started to appreciate that the philosophical demarcations of ontology, axiology, epistemology, and methodology, were not just academic concepts, but deeply personal explorations into some of the most probing and potent questions humanity can ask. As I have engaged with these questions through the medium of this study, the process of arriving at firm convictions (documented in Chapter 3) has revealed not just my academic and philosophical perspective, but my personal and theological convictions. I have truly valued this quest into the unknown.

I remember the practical challenges I encountered along my journey. Having gained ethical approval to embark upon my research in April 2013 I had scheduled a three week window in May/June 2013, to undertake my first round of interviews with parents. This seemed like a realistic and reasonable timeframe. However, I faced practical delays in gaining initial access to contact information for parents. Unforeseen changes in staff, and unexpected restrictions, caused an unanticipated delay. This lost time was particularly significant because at this stage of the study I was based in the USA and had travelled to Ireland for three weeks. I could not extend my stay to accommodate this delay. Despite my best efforts it seemed like

my plans to interview were not going to transpire, and as my time in Ireland was running out it appeared that it would pass without a single interview. This delay could potentially have affected not only my interview schedule, but my entire timeframe for this study, as I knew I would not be back in Ireland for a number of months. However, with help from my supervisor, and the assistance of key professionals, we persisted in tackling these delays. After much effort they were eventually resolved and the information I needed was released to me. I subsequently posted out my first letters to interview, with much celebration, relief, and thankfulness. Within days I received three affirmative responses, and had just enough time to complete them before returning to the USA. While there was a positive outcome to this challenge, I learned that what seemed like a simple process, was inexorably more complicated than I expected. To paraphrase William Shakespeare, I discovered that "the course of [research] never did run smooth".

I remember the very first interview I conducted with a parent. I arranged the interview with nervous anticipation, standing in the divide between the certainty of prior preparation, and the uncertainty of what lay ahead. I sat with the parent, self-consciously at first, running through the introductions and conditions, feeling a pang of uneasiness as I initiated such a personal interview. However, as we began to gently unravel her story, she gradually opened up her life. The honestly of her self-disclosure dissipated my self-consciousness and I soon became absorbed in every word. As I listened to her story, I was deeply moved by the rawness of her grief. I was struck by the loneliness of her experience. I felt the pain of her struggles. As I reflect on this interview, and the others that followed, many of my preconceptions were challenged. I did not expect to encounter such depth of loss. I did not anticipate such heights of resilience. I did not realise the plethora of roles parents assume as they care for their child. I did not foresee the subtle complications of these responsibilities. I could not have anticipated the specific frustrations parents faced in their journey. I had not considered the sense of ethical responsibility parents felt in advocating for their child's needs. I did not fully appreciate the

solidarity of community. Having conducted the interviews, and become engrossed in the subsequent analysis, I returned to the literature with a changed perspective. Articles that I had previously seen as authoritative, I now read with a critical eye. Principles I previously embraced, I now refuted. This resulted in the lively critique embedded within the Discussion Chapter of this study (Chapter 7) which captured the change in my outlook.

I remember confronting the preconceptions that I did not even realise I had. Before I even began embarking upon field research, I encountered the counselling concept of a "crisis" which has a three-fold definition:

> A crisis is a situation in which there is a precipitating stressor event, a perception of that event that leads to distress, and diminished functioning when the distress is not relieved by familiar coping resources (Puleo & McGlothin, 2010, p.24).

This concept lodged in my memory as a potentially compelling way of depicting the parental experience. Unbeknown to myself at this time, this fostered a preconceived expectation. My reading of the literature further substantiated this preconception, as the description of parental grief was consistent with this concept. After my early interviews with parents, my preconception seemed to be confirmed by the analysis of data. I therefore felt justified in employing the language of "crisis" as I classified codes under what I thought was an appropriate concept. As I continued to collect and analyse data, the conceptual framework of this study began to take shape my four stages were even entitled

> Stage #1: Impending crisis
> Stage #2: Confirmed crisis
> Stage #3: Initial coping
> Stage #4: Ongoing coping

However, while the stages themselves were confirmed by further research, the language and underlying assumption of a crisis was undermined.

I remember that as I continued to collect and analyse data, I began to realise, and initially resist, the increasing challenge to my use of this conceptual classification. When

encountering particularly optimistic parents in interviews, I was initially confused as I wrestled with how to represent their hopeful, resilient, and positive experiences during the diagnostic phase. This data undermined my classification of an "impending crisis" within Stage #1, and a "confirmed crisis" within Stage #2. I persisted in trying to somehow reconcile the concept of crisis with these surprising findings, however the continued analysis of data, as well as conversations with my supervisor, refuted my preconceptions to such an extent that I discarded the concept and renamed my stages. I realised through supervision that I needed to employ more neutral language for each stage that captured the diverse range of parental experiences.

I remember the challenge to maintain the original intent of this study. When inviting professionals to participate I was resolute in my reassurance that this study is not a second NARG Report. While this study was intended to make recommendations for improving the system, I emphasised that I was concerned with the process of parental coping, not with assessing professional practice. However, in reality, I was surprised that this distinction was more ambiguous and difficult to maintain than I realised. When parents within my sample highlighted specific difficulties they encountered within their four-stage journey, there was inevitably an underlying assessment of the proficiency of the UNHS system. This could not be avoided because these issues deeply impacted their experiences of receiving and responding to an early diagnosis. My preconceived boundary between critical evaluation and parental coping was therefore challenged. To remain true to my original intent, I presented these issues with great care and caution. I repeatedly affirmed the professionals who operated within the UNHS system and presented any difficulties as generic rather than specific to one particular service within one particular geographical region. The difficulties, and subsequent recommendations, were also identified in order to support parents rather than to represent a thorough assessment of services. This safeguarded against any pointed critique of individuals or particular services and maintained the original emphasis of the study.

I remember the academic challenges I faced. During the analysis of data I struggled with the formulaic methodological instructions of the Straussian Grounded Theory and battled with the restrictions of the computer programme NVivo. I eventually discarded the latter and relaxed the former (this tension and resolution is relayed in detail in section 5.7 of Chapter 5, and illustrated in Appendix E). However, the relief and freedom that this decision precipitated had two significant consequences. Firstly, the process of analysing and coding interviews was now manual, which represented a more time-consuming endeavour. Secondly, after four rounds of interviews, the sheer volume of analysed data (overflowing with codes and categories) was difficult to manage. While I consistently printed out the codes, meticulously categorised them, and coherently hung them on my wall (see the visual diary in Appendix E), it became increasingly difficult to collate the vast quantity of data. I felt like I was drowning in the complexity and density of my ongoing analysis. The thought of attempting to present this information within this study in a comprehensive format was overwhelming. I did not regret my decision to operate manually - it precipitated a more creative engagement with the data. In addition, had I worked with the data digitally I very likely would have faced the same challenge of volume, complexity, and density. One of the greatest learning points of this study was the slow process of confronting my reticence to translate these codes and categories into a chapter for this thesis. This slow, laboursome endeavour necessitated distilling the essence of each concept and presenting it succinctly. It required writing draft, upon draft, upon draft of the Findings Chapter, which compelled me to rigorously refine the emergent conceptual framework, labouring over every detail. This translation was one of the most arduous but rewarding endeavours of this study.

While all the above milestones represent key events, the process of undertaking this study was a day-by-day endeavour, which continually challenged me. Along this journey, I often reflected on Wendell Berry's poem X (Berry, 2013, p.20).

> Whatever is foreseen in joy
> Must be lived out from day to day.
> Vision held open in the dark
> By our ten thousand days of work.
> Harvest will fill the barn; for that
> The hand must ache, the face must sweat.

There were times over the past three years I felt the strain of "ten thousand days of work", the "ache" of my hand as I revised yet another chapter, the stress of struggling to overcome challenges in the study, the "sweat" of edit upon edit (Berry, 2013, p.20). In the midst of this labour I clung to the "vision held open in the dark" of a meaningful research endeavour with the potential for positive outcomes (Berry, 2013, p.20). While this was "foreseen in joy" it had to be "lived out from day to day" with early morning starts, and work that stretched long into the midnight hours (Berry, 2013, p.20).

However, Berry's depiction of laboursome toil takes an unexpected change of direction, which captivated my mind throughout this study. He writes (Berry, 2013, p.20):

> And yet no leaf or grain is filled
> By work of ours; the field is tilled
> And left to grace. That we may reap,
> Great work is done while we're asleep.

Berry employs the image of a farmer who can only create the conditions to grow a crop, but cannot create the crop itself. This "great work" of growth is silently and slowly manifesting while the finite farmer is "asleep" (Berry, 2013, p.20). These words have deeply resonated with me and I have spent long hours reflecting on them. So much of this study has been outside of my sphere of influence. I did not write the funding grant to generate income for this study. I was not on the interview panel selecting the candidate to undertake it. I had never met my appointed supervisor before this opportunity arose. I was not on the ethics committee evaluating my research proposal. I could not ensure I would gain access to the contact information I needed having travelled from abroad. I had no control over what families names would be released to me by the HSE. I had no idea who would respond to the invitation to

interview. I could not predict what stories my participants would disclose to me. I could not govern how many families would engage in a participant check. I could not control their subsequent evaluation of my research. And I now have little capacity to determine what impact the findings will (or will not) have as I hope to disseminate them. Thus, while I have worked hard on this study, I operate in the context of my own finitude. To speak in metaphor, although I have ploughed and planted seeds, "no leaf or grain is filled" by my power (Berry, 1998, p.20). Significantly, "there is no guaranteed result attached to the farmers efforts" (Reese & Loane, 2012, p.218). The work is ultimately "left to grace. That we may reap, Great work is done while we're asleep" (Berry, 1998, p.20).

In this poem Berry is contrasting two different approaches to work. The "ache" of "ten thousand days of work" in the opening stanza is juxtaposed with this second illustration of working within the context of rest, stillness, and peace (Berry, 1998, p.20). The farmer in the latter illustration "recognizes both the necessity and the modesty of his or her part in the whole. The posture is not one of control, but of cooperating with the Maker of all things" (Reese & Loane, 2012, p.218). Consequently, "this trust or faith resonates through all the farmer's labours and rest, all successes and failures. It is a blend of trust and effort, foresight and reverence, resolve and patience" (Reese & Loane, 2012, p.218).

The nuances of these words have deeply resonated with me. I repeated them to myself during countless stages of this study, from preliminary preparation, to data collection, to analysis, to application. Throughout this research, I have struggled against the urge to carry the weight of the study on my shoulders alone, and to see the completion as a product of my time, effort, and ability. Instead I seek to work in the context of grace, resting in the peace that the greater work of God infuses and supersedes my work. The harvest is ultimately a gift.

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11. Appendices

Appendix A: Table 11.1 Citation Analysis (CA) for Literature Review

This citation analysis (CA) was undertaken in April 2014 with the aid of the academic database Scopus. The articles are ranked according to their CA, and methodological details are included.

Author, Year *& Article*	CA	Research Design	Research Paradigm	Strategy of Inquiry	Research Tools	Data Analysis	Sample
Bess & Paradise, 1994: *Universal Screening for Infant Hearing Impairment: Not Simple, Not Risk-Free, Not Necessarily Beneficial, and Not Presently Justified*	213[36]	Discussion article which references literature	N/A	N/A	References to literature	N/A	N/A
Yoshinaga-Itano, 2003: *From Screening to Early Identification and Intervention: Discovering Predictors to Successful Outcomes for Children With Significant Hearing Loss*	205[37]	Quantitative research, drawing on data from a longitudinal series of studies	Not stated	Not stated	The parental stress index; videotaped observations of mother-baby interactions (in the applicable section)	Quantitative analysis of the parental stress index and emotional availability scales	Not defined
Yoshinaga-Itano, 2003: *Early Intervention after Universal Neonatal Hearing Screening: Impact on Outcomes*	96	Quantitative research based on a series of studies in Colorado	Not stated	Not stated	The parental stress index; the parenting events/daily hassles scale (in the applicable section)	Quantitative analysis of scales and measurements	Not defined
Clemens et al., 2000: *The False-Positive in Universal Newborn Hearing Screening*	69	Quantitative, retrospective analysis	Not stated	Not stated	Structured telephone survey; data from hospital records	Statistical analysis undertaken with SPSS; Fisher's exact test for measuring anxiety	Not defined
Magnuson & Hergils, 1999: *The parents' view on hearing screening in newborns - Feelings, thoughts and opinions on otoacoustic emissions screening.*	42	Qualitative study	Not stated	Not stated	Interviewing with open-ended questions and dialogue; field notes of the researcher's observations	General qualitative analysis	Not defined
Paradise, 1999: *Universal Newborn Hearing Screening: Should We Leap Before We Look?*	38	Discussion article which references literature	N/A	N/A	References to literature	N/A	N/A
Kurtzer-White & Luterman, 2003: *Families and children with hearing loss: grief and coping.*	36	Discussion article which references literature	N/A	N/A	References to literature	N/A	N/A
Young & Tattersall, 2007: *Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development.*	35	Qualitative interview study	Not stated	Not stated	Interviewing; simple questionnaire for sociodemographic information	Thematic content analysis; use of QSR NUD*IST computer software	Pur-posive sample

[36] According to Google Scholar - not available on Scopus
[37] According to Google Scholar - not available on Scopus

Author, Year *& Article*	CA	Research Design	Research Paradigm	Strategy of Inquiry	Research Tools	Data Analysis	Sample
Lutterman & Kurtzer-White, 1999: *Identifying hearing loss: Parents' Needs.*	33	Retrospective, qualitative survey on parental perspectives	Not stated	Not stated	Survey - five item questionnaire with open-ended questions	Unspecified	Not classified
Hergils & Hergils, 2000: *Universal neonatal hearing screening - parental attitudes and concern.*	26	Qualitative Study addressing parental attitudes and concerns	Not stated	Not stated	Questionnaire with open-ended questions	Appears to be a thematic analysis	Not classified
Russ, et al., 2004: *Qualitative analysis of parents' experience with early detection of hearing loss*	24	Qualitative semi-structured questionnaire with parents	Not stated	Not stated	Qualitative questionnaire with open-ended questions; data from hospital records	Thematic analysis	Not classified
Yoshinaga-Itano, 2003: *Universal Newborn Hearing Screening Programs and Developmental Outcomes*	22	Drawing on quantitative data from a longitudinal series of studies from 1994 to 2001 in Colorado	Not stated	Not stated	(In the applicable section) the parental stress index; the parenting events/daily hassles scale; the family support scale; observations of mother-baby interactions	Quantitative analysis of the three indexes; use of scales to measure mother-baby interaction	Not classified
Fitzpatrick et al., 2007: *Parents' perspectives on the impact of the early diagnosis of childhood hearing loss*	21	Mixed methods research inquiry exploring parental perspectives	Not stated	Not stated (but the analysis implies elements of grounded theory)	Semi-structured interview with open-ended questions; family information questionnaire, intake questionnaire, demographic questionnaire; field Notes	Qualitative analysis (constant comparative method); ATLAS qualitative research software	Purposive sample (but could also be classified as a theoretical sample)
Spahn et al., 2003: *A comparison between parents of children with cochlear implants and parents of children with hearing aids regarding parental distress and treatment expectations*	21	Quantitative cross section study comparing two cohorts of parents	Not stated	Not stated	Quantitative questionnaires relating to sociodemographic data, hearing aids/cochlear implants, self-assessment for emotional state, family climate scale	Quantitative evaluation with SPSS 10, the t-test for independent samples, the chi square test, Pearson's correlation coefficients	Not classified
Young et al, 2006: *Informed choice and deaf children: underpinning concepts and enduring challenges*.	20	Metastudy: comprehensive literature review	N/A	N/A	Comprehensive literature search (use of 10 databases for comprehensive electronic literature search)	Thematic grouping with conceptual categories and sub-categories	N/A
DesGeorges, 2003: *Family perceptions of early hearing, detection and intervention systems: Listening to and learning form families.*	19	Discussion article which references parental experiences and literature	N/A	N/A	References to literature; summary of specific family's experience	N/A	Not classified

Author, Year *& Article*	CA	Research Design	Research Paradigm	Strategy of Inquiry	Research Tools	Data Analysis	Sample
Young & Tattersall, 2005: *Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening.*	19	Qualitative, narrative-interview study exploring parental evaluation of services	Not stated	Not stated	Qualitative - narrative interview	Thematic content analysis with cross sectional techniques, within-case and cross-case perspectives.	Purposive sample
Vohr et al, 2008: *Results of newborn screening for hearing loss: effects on the family in the first 2 years of life.*	17	Matched cohort analytic study, prospective longitudinal study.	Not stated	Not stated	Hollingshed four factor index of social status, family support scale, family resource scale, impact on family-adapted version G scale, parenting stress scale; demographic data, neonatal data, and screening results from two databases.	Quantitative questionnaires scored according to applicable measurement with attention to variables	Not classified
Fitzpatrick et al., 2008: *Parents' Needs Following Identification of Childhood Hearing Loss.*	16	Qualitative study exploring parental needs	Not stated	Not stated clearly (but describe a grounded theory analysis)	Semi-structured interviews; interviewer notes	Analysed with Straussian grounded theory (coding, memo writing, saturation etc.)	Purposive sample (but could be classified as a theoretical sample)
Tattersall & Young, 2006: *Deaf children identified through newborn hearing screening: parents' experiences of the diagnostic process.*	15	Qualitative descriptive research privileging parental perspective	Not stated	Not stated	Interviews - narrative based qualitative method; literature review,	Thematic content analysis, cross sectional techniques; use of QSR NUD*IST4 software	Purposive sample
Porter, 2007: *Parents of Deaf Children Seeking Hearing Loss-Related Information on the Internet: the Australian Experience.*	14	Online mixed methods questionnaire exploring parental use of internet	Not stated	Not stated	An online questionnaire with a mix of single (yes/no) questions, multiple-choice questions, and open-text questions	Quantitative data analysed using Pearson chi-square test, frequency distribution and cross-tabulations	Not Classified
Weichbold et al, 2001: *The impact of information on maternal attitudes towards universal neonatal hearing screening*	12	Quantitative study designed to test a hypothesis	Not stated	Not stated	Semi-standardised interview with mothers by means of predefined questions	The closed questions were scored according to specific indicators	Not Classified
Desjardin , 2003: *Assessing Parental Perceptions of Self-Efficacy and Involvement in Families of Young Children with Hearing Loss*	9	Discussion article which presents a tool to measure perceptions of self-efficacy and involvement.	N/A	N/A	References to literature, critical evaluation of research tools	N/A	N/A

Author, Year ***& Article***	CA	Research Design	Research Paradigm	Strategy of Inquiry	Research Tools	Data Analysis	Sample
McCracken et al., 2008: *Universal newborn hearing screening: Parental reflections on very early audiological management*	9	Qualitative narrative study	Not stated in abstract (Full article unavailable)	Not stated in abstract	Qualitative and narrative study	Unspecified in abstract	Not classified in abstract
Young, 1999: *Hearing parents' adjustment to a deaf child - The impact of a cultural-linguistic model of deafness*	8	Qualitative interview study	Not stated	Not stated clearly (but see data analysis)	Semi-structured interviews	Ethnographic content analysis	Not classified
Young et al, 2004: *To What Extent Do the Characteristics of the Object of Evaluation Influence the Choice of Epistemological Framework? The Case of Universal Newborn Hearing Screening.*	8	Discussion article which references literature	N/A	N/A	References to literature and to evaluations	N/A	N/A
Mohd Khairi et al., 2011: *Anxiety of the mothers with referred baby during Universal Newborn Hearing Screening*	8	Cross Sectional Study	Not stated	Not stated	Face-to-face interviews; the Malay translation beck anxiety Inventory (BAI) questionnaire	Computer software SPSS programme, Wilcoxon signed Rank Test (for comparing levels of anxiety)	Simple random sampling
Jackson, et al., 2010: *Family quality of life following early identification of deafness*	7	Mixed methods (quantitative and qualitative) questionnaire	Not stated	Not stated	Questionnaire which encompassed a "scale of family quality of life"	Quantification of questionnaire, descriptive analysis	Not classified
MacNeil, 2007: *Evaluating Families' Satisfaction With Early Hearing Detection and Intervention Services in Massachusetts.*	7	Quantitative survey measuring families' satisfaction and anxiety	Not stated	Not stated	Three separate surveys were designed for three separate study groups	Use of Microsoft access databases, SAS, and chi-square statistics	Not classified
Luterman , 1999: *Counselling Families with a Hearing- Impaired Child*	6	Appears to be a discussion article with reference to literature (As evident in abstract - full article unavailable)	N/A	N/A	Appears to be akin to Lutterman's comparable articles which draw on literature and professional experience	N/A	N/A
Yucel, 2008: *The needs of hearing impaired children's parents who attend to auditory verbal therapy-counselling program*	6	Quantitative survey to explore parents' needs for information and support	Not stated	Not stated	The family needs survey (adapted version for families of children who are deaf or hard of hearing)	Statistical analysis with SPSS-10 computer software, Kruskal—Wallis Ztest	Random
Gibley, 2010: *Qualitative analysis of parents' experience with receiving the news of the detection of their child's hearing loss*	6	Qualitative interview study with quantitative questionnaire	Not stated	Not stated	Semi-structured interviews; a survey questionnaire recording demographic information	Thematic analysis	Not classified

Author, Year *& Article*	CA	Research Design	Research Paradigm	Strategy of Inquiry	Research Tools	Data Analysis	Sample
Lutterman, 2004: *Counselling Families of Children with Hearing Loss and Special Needs*	5	Discussion article	N/A	N/A	Computer search for literature, professional experience, review of files with statistical inferences	N/A	N/A
Lutterman, 1997: *Emotional Aspects of Hearing Loss*	5	Discussion article	N/A	N/A	Literature	N/A	N/A
Minchom, 2003: *Service needs of hearing-impaired children and their families: report of a survey of parental attitudes.*	5	Medical research council questionnaire and interview	Not stated in abstract (full article unavailable)	Not stated in abstract	Questionnaire; semi-structured interview	Not stated in abstract	Not classified (within the abstract)
Hardonk et al, 2011: *Congenitally Deaf Children's Care Trajectories in the Context of Universal Neonatal Hearing Screening: A Qualitative Study of the Parental Experiences*	5	Qualitative research with phenomeno-logical analysis	Not stated	Not stated clearly, but data analysis implies phenom-enology	Semi-structured interviews, with questions based on literature, and which included a life-grid method	Analysis based on a phenomen-ological approach with thematic content analysis	First wave of data collection – not classified Second wave - Intentional sample
Van Der Ploeg, 2008: *Examination of long-lasting parental concern after false-positive results of neonatal hearing screening*	5	Quantitative research design	Not stated in abstract (full article unavailable)	Not stated in abstract	State-trait anxiety inventory (STAI) measurement	Quantitative analysis of scores	Random sampling (for one group) The second group is not classified
Young et al, 2009: *The Design and Validation of a Parent-Report Questionnaire for Assessing the Characteristics and Quality of Early Intervention over time (MVOS questionnaire - My Views on the Services)*	4	Discussion of quantitative study (justifying the design of the parent-report repeat questionnaire)	Not stated	Not stated	Parent-report repeat questionnaire; trait emotional intelligence questionnaire; parental focus group, and interviews	Not stated clearly	Not classified
Matthijs, 2012: *First Information Parents Receive After UNHS Detection of Their Baby's Hearing Loss.*	3	Qualitative, inductive study	Not stated	Not stated, but data analysis implies inter-pretive phenom-enology and discourse analysis	Semi-structured interviews with open-ended questions	Interpretative phenomen-ological analysis, discourse analysis, MAXQDA software package for qualitative analysis	Purposive sampling
Meinzen-Derr et al., 2008: *Paediatric Hearing Impairment Caregiver Experience: Impact of Duration of Hearing Loss on Parental Stress*	2	Cross sectional design with quantitative questionnaire to measure stress	Not stated	Not stated	68-item paediatric hearing impairment caregiver experience (PHICE) questionnaire, collection of demographic information	Quantitative analysis (domain and z-scores) of trends of stress over time	Not classified

Appendix B: An Explanation of Symbolic Interactionism and Pragmatism

While Straussian GT, which is broadly post-positivist, the composition of the methodology was deeply influenced by the more specific philosophical demarcation of symbolic interactionism and pragmatism (Strauss & Corbin, 1990, 1998). There was not the scope in Chapter 4 to examine these philosophical positions which Strauss and Corbin employ as a hermeneutic with Straussian GT, hence the inclusion of this brief explanation.

There is a distinction between symbolic interactionism and non-symbolic interactionism (Blumer, 1986). Blumer explicated that non-symbolic interaction occurs when an individual reacts directly to an action, circumstance, etc. without prior reflection or interpretation (Blumer, 1986). This may encompass impulsive, immediate, reflex, or automatic responses. In contrast, symbolic interaction encompasses a contemplation and interpretation of the action or situation (Blumer, 1986). Thus, within symbolic interaction, the individual responds on the basis of the meanings (or symbols) they interpret (Blumer, 1986). Accordingly, people interact with one another on the basis of interpreted meaning and respond to circumstances on the basis of how they subjectively interpret a situation (Aldiabat & Le Navenec, 2011, p. 1065, 1067). Thus, Corbin and Strauss contended that the individual lives in a "symbolic universe", infused with meanings which are shared and disputed, created and recreated, defined and redefined, interpreted and reinterpreted through a complex web of social interaction (Corbin & Strauss, 2008, p. 6). Furthermore, in keeping with the pragmatist tradition, Strauss and Corbin argue that the ultimate analysis of interpretation and perception is located in the resultant action of the individual as they seek to resolve a situation (Corbin & Strauss, 2008).

Symbolic interactionism and pragmatism permeate Straussian GT. As well as solidifying an emphasis on interaction, interpretation, meaning, and resultant actions, this philosophical position also informs the Straussian GT objective to conceptualise "human behaviour as a social process among actors in their interactional context" (Aldiabat & Le Navenec, 2011, p. 1068).

Appendix C: Letter of Ethical Approval from the Clinical Research Ethics Committee (for Interviewing Parents and Professionals)

Ireland.

Ireland

Our ref: ECM 4 (mm) 09/04/13

28th March 2013

Dr Robert Fourie
Lecturer
Department of Speech and Hearing
University College Cork
Brookfield Health Sciences Complex
College Road
Cork

Re: A qualitative analysis of parental coping following early diagnosis of hearing loss in Ireland.

Dear Dr Fourie

Expedited approval is granted to carry out the above study at:

- University College Cork.

The following documents have been approved:

- Signed Application Form
- Parental Invitation Letter dated 12th March 2013
- Parental Information Sheet
- Interview Guide for Parents
- Consent Form for Parents
- Invitation Letter for Clinicians dated 12th March 2013
- Information Sheet for Clinicians
- Interview Questions for Clinicians
- Consent Form for Clinicians
- Semi-structured interview questions.

We note that the co-investigator involved in this study will be:

- Meabh Kenny.

Yours sincerely

Professor Michael G Molloy
Chairman
Clinical Research Ethics Committee
of the Cork T

Appendix D: Participant Check

i. DVD Created for Participant Check

This DVD encapsulates a very short 15 minute summary of the overarching research findings of this study. It was distributed to parents within this study sample who (having previously participated in an interview) expressed interest in evaluating the findings of this study through the medium of a participant check.

ii. Questionnaire for Participant Check

Questionnaire

Following the DVD Presentation of Research

Below, you will find 15 statements regarding the presentation you have just seen. I would be very grateful if you would place a tick in the box that represents your agreement or disagreement with each statement. Feel free to evaluate each statement as negatively or positively as you believe is true. Your honest opinion is very important.

Statement	*Strongly* ***Disagree***	***Disagree***	***Neither Agree nor Disagree***	***Agree***	***Strongly Agree***
1. This model reflects my experience					
2. The model is a helpful illustration of my journey					
3. The description of anxiety, while waiting for a diagnosis, is appropriate					
4. It is the audiologist's role to prepare parents for receiving a diagnosis					
5. The explanation of emotional responses in this study are true to my experience					
6. Hearing loss professionals should be trained to support parents emotionally					
7. I experienced at least one of the coping mechanisms explained in the presentation					
8. Connecting with other families is beneficial for coping with the hearing loss diagnosis					
9. Hearing loss professionals should facilitate family to family connections					
10. I have experienced most of the parental roles described in the presentation.					

11. I have experienced some of the problems in the system.					
12. I agree with the two principles of parent-child interaction					
13. I agree with the recommendations.					
14. I think professionals should be made aware of this model.					
15. Early identification of hearing loss has benefitted my child.					

Please use the lines below if you wish to make any further comments

iii. Letter of Ethical Approval from the Clinical Research Ethics Committee (to Undertake the Participant Check)

UCC

COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee

Tel: + 353-21-490 1901
Fax: + 353-21-490 1919

Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

~~Our ref: ECM 3 (qqqqqqq) 06/01/15~~

6th January 2015

Dr Robert Fourie
Lecturer
Department of Speech and Hearing
University College Cork
Brookfield Health Sciences Complex
College Road
Cork

Re: A qualitative analysis of parental coping following early diagnosis of hearing loss in Ireland.

Dear Dr Fourie

The Chairman approved the following:

- Amendment Application Form
- Letter of Invitation/Information Sheet for Parents
- Consent Form
- Presentation Script
- Questionnaire.

Yours sincerely

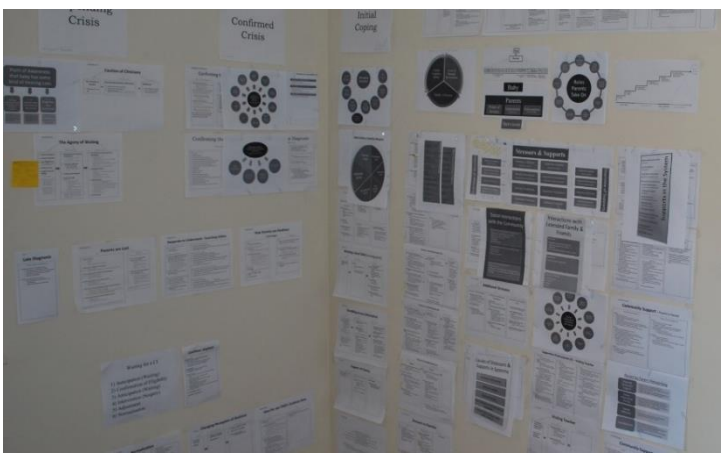
Professor Michael G Molloy
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

Appendix E: A Visual Diary of Coding

The following photographs (and the accompanying personal explanations) provide a visual diary of the researcher's experience coding each round of interviews (described in Chapter 5.7)

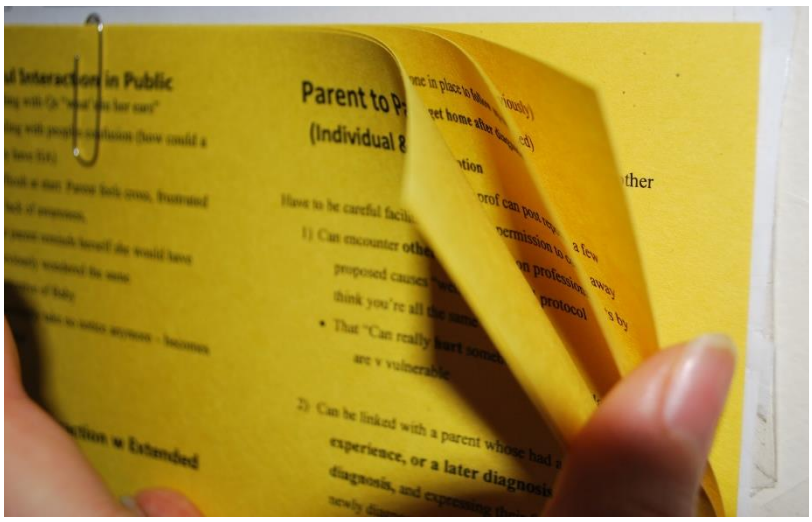
Round #1of Coding



Initially, when I undertook the first round of coding, I employed a computer software programme called NVivo. However, the more I used the software, the more restricted I felt in its capacity to represent my coding visually. As a visual thinker, I started to draw out the codes and categories manually, and pin them to my wall. I found this vastly more helpful as it enabled a visual engagement with the data, allowing me to take in the breadth of codes in one glance and reorder categories accordingly. At this point I was employing both NVivo and this manual method simultaneously.

As my analysis progressed, I found the manual and visual form of coding more helpful while I found the software more obstructive. Consequently, I switched to a completely manual form of coding which I undertook in a more systematic capacity by typing up all my codes and categories. This was more time consuming, but for a visual thinker like me, it was a far more effective approach to coding. I also started to illustrate conceptual categories with diagrams to visually depict dominant concepts as my analysis matured.

Round #2 of Coding

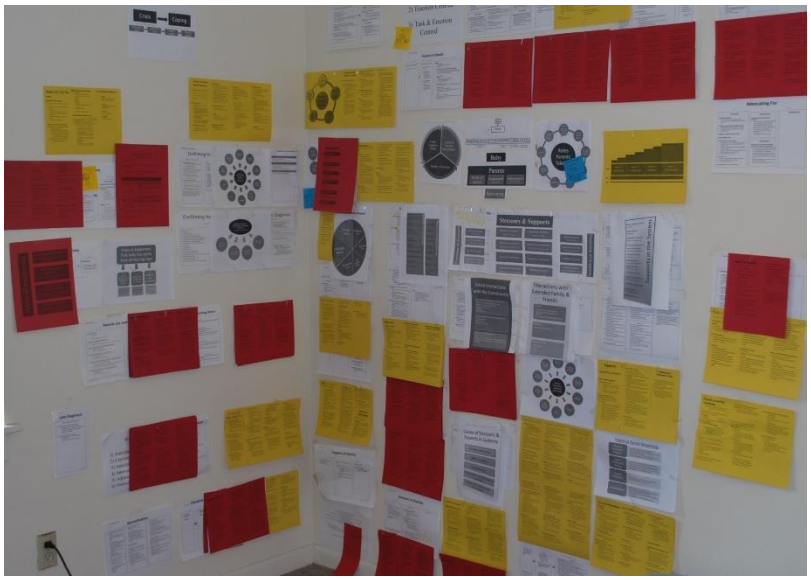


When I undertook, transcribed, and coded the second round of interviews I decided to print the subsequent codes and categories on yellow paper so that it could be clearly distinguishable.

At this point the categorisations were becoming dense and complex and I was running out of space to hang them on my wall. Consequently, I had to layer pages of codes, and sub-categories.

My tentative, overarching hypothesis (of distinct stages of parental coping with an early diagnosis of infant hearing loss) had begun to manifest as early as the first round of data analysis. During this second round of data collection and coding, I began to refine this conceptual framework. It underwent significant maturation as I continued to fine-tune the coding, categorisations, and concepts.

Round #3 of Coding

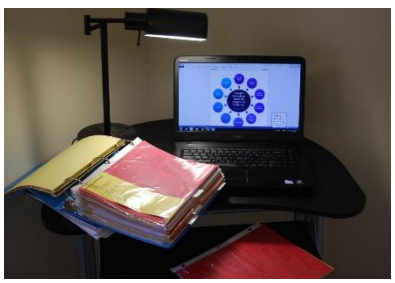


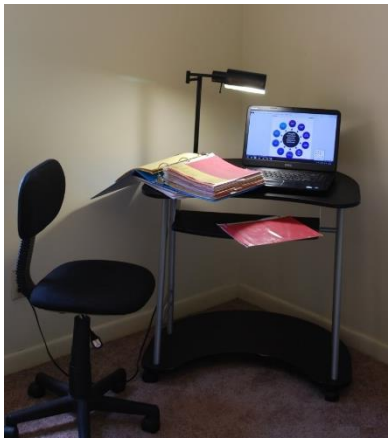
I coded the subsequent round of interviews on red paper, again, to differentiate the third round of coding from the previous two. As space was a considerable issue the categories of codes were hung in many layers.

At this point the categorisations were dense and complex and the emerging hypothesis was surfacing. I was beginning to reach the point of saturation, where no new data was challenging my concepts. I now needed to integrate (or reduce) the categories into higher-level substantive concepts to reach a higher level of conceptualisation and solidify my hypothesis.

The challenge at this point became how to manage this volume of data. I had been so immersed in this coding process (for over a year) that the prospect of integrating and translating this volume of coding into a comprehensive explanation, understandable to someone outside of the process, was overwhelming

Managing the Volume of Coding



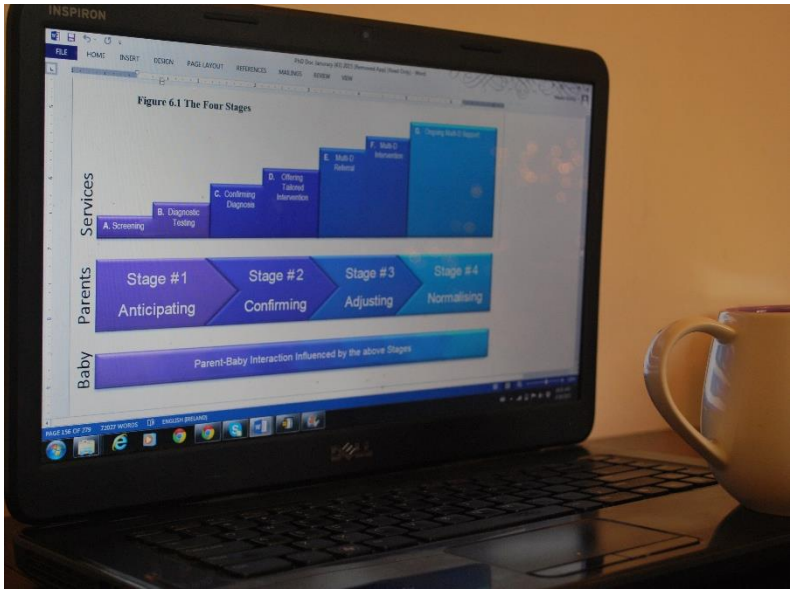


It soon became clear that in order to manage this volume of data and refine my hypothesis, I needed to dismantle my coding wall and integrate the categories into higher-order conceptual categorisations (selective coding).

I proceeded to dismantle the wall of analysis to collate the array of codes and categorisations under their applicable higher-order categories. I then collated all the contents of the higher-order category into one plastic pocket to represent one unit. I subsequently integrated these units into higher-level concepts again creating a hierarchy. This resulted in one core category which subsumed all the previous codes and categories.

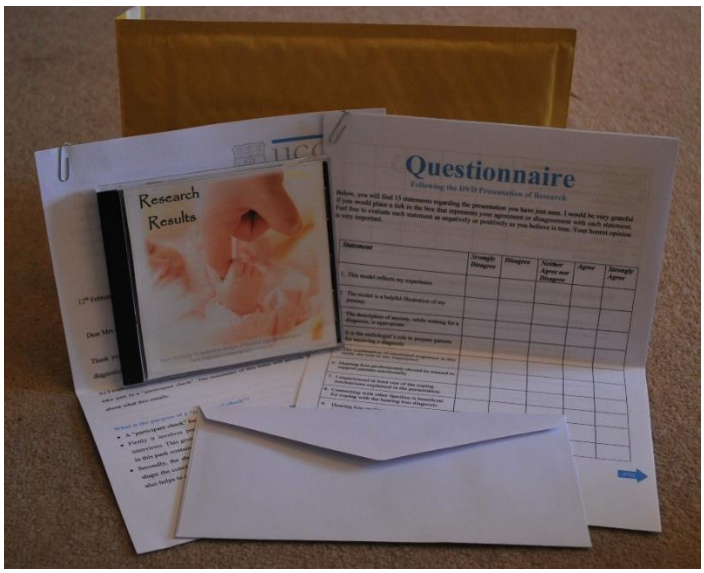
The core category consisted of four dense sub-categories (four stages), which encapsulated my conceptual framework. I filed the hierarchy of categorisations in a folder and began typing up this conceptualisation into a written chapter to strive to articulate my framework succinctly.

Round #4 of Coding



I subsequently undertook one final round of interviewing, which I subsequently coded and printed on blue paper. In this final round of interviewing I encountered a number of anomaly cases (in particular the unique dynamics of a dual-diagnosis, potential medical complications, or a previous family history of hearing loss). I integrated this fourth round of codes into my conceptualisation. While greatly enhancing the findings, they did not alter the overarching conceptual framework which had the flexibility to account for these differences. The conceptual framework was therefore complete. The act of translating it into a chapter of this study necessitated a balance between complexity and simplicity. While this was a tremendous challenge, it served to refine the concepts significantly. At this point I also began comparing the conceptual framework to the literature and writing a Discussion Chapter.

Participant Check



Having refined the resultant conceptual framework, the need to corroborate this conceptualisation with a participant check became increasingly evident to me. This consisted of presenting the conceptualisation of the study to the parents (who participated in interviews) and requesting their assessment. The resultant evaluation tests the trustworthiness of the research findings. Due to the geographical remoteness and diversity of the participants, the most effective means to undertake this was by post.

Having sought and gained ethical approval, I created the DVD of the research findings (see Appendix D). I proceeded to post this to parents along with a letter / information sheet, consent form, two evaluation forms and stamped, addressed envelope. I posted a total of 18 evaluation forms (to 9 families) and in response received 6 completed forms (from 4 families). These assessments were analysed and used to generate descriptive statistics which were incorporated into the Findings Chapter of this study. As well as substantiating the conceptualisation of this study, the participant check also gave parents very early access to the research findings. It was also an important means of prioritising the parents' voice and valuing their assessment of this study.

Appendix F: Publications arising from this Study

i. First Published Journal Article

The Qualitative Report 2014 Volume 19, Article 103, 1-9
http://www.nova.edu/ssss/QR/QR19/kenny103.pdf

Tracing the History of Grounded Theory Methodology: From Formation to Fragmentation

Méabh Kenny and Robert Fourie
University College Cork, Corcaigh, Ireland

There are very few articles, which track the history of Grounded Theory (GT) methodology from its tentative conception to its present divisions. This journal article addresses the dearth by tracing the history of GT methodology from its conception in the 1960's, discussing the context of its composition, character, and contribution. Subsequently, the article follows the maturation of GT which is characterised by a series of contentious and, at times, antagonistic academic debates. The crux of these debates centres on disputes over core tenets of GT and have resulted in three dominant and divergent configurations of the GT methodology: Classic, Straussian, and Constructivist GT. These factions can often create confusion for the researcher wishing to embark on a GT study. However, an examination of the history of the GT methodology sheds light on the logic of these schisms. Keywords: Classic Grounded Theory, Straussian Grounded Theory, Constructivist Grounded Theory, History of Grounded Theory, Development of Grounded Theory, Differences between Grounded Theories, Grounded Theory Methodology, Glaser, Strauss and Corbin, Charmaz

Grounded theory was the innovative brainchild of two American Sociologists, Barney G. Glaser and Anselm L. Strauss. Prior to meeting each other, Anselm Strauss received his BS in Biology from the University of Virginia (1939). He subsequently completed both his MA and PhD in sociology in the University of Chicago (1942, 1945). In 1960, at the age of 44, Strauss undertook an academic post with the University of California, San Francisco (UCSF), where he later established and chaired a doctoral programme in sociology, assuming the role of director (Dicke, 1996; Birks & Mills, 2011). Meanwhile, Barney Glaser received a BA degree from Stanford University (1952). During two subsequent years of military services, he also studied literature at the Sorbonne University of Paris (France) and the University of Freiburg (Germany). With a strong aptitude for academics, Glaser later proceeded to embark upon a PhD in Columbia University (1961). On completion of his PhD, 33- year-old Glaser pursued a research alliance with Strauss in the University of California, San Francisco. At the time, Strauss had applied for, and successfully received, a grant to pursue a funded four-year research endeavour. Subsequently, Strauss recruited Glaser and together they undertook a study relating to interactions between medical staff and terminally ill patients in hospices, which they later titled the *Awareness of Dying* (1965).

The Genesis of Grounded Theory

Grounded theory was forged against the backdrop of Glaser and Strauss' disenchantment while undertaking the *Awareness of Dying* (1965) study. During this research Glaser and Strauss encountered and criticized the "overemphasis" of verifying theories to the detriment of actually generating the theory itself (Glaser & Strauss, 1967; Moore, 2009). They asserted that the twofold process of firstly generating and subsequently verifying a theory should receive equal treatment within social research. However, they observed that "since

verification has primacy on the current sociological scene, the desire to generate theory often becomes secondary, if not totally lost, in specific researches" (Glaser & Strauss, 1967, p. 2). As well as encountering a misplaced emphasis on verification, Glaser and Strauss also criticized the dearth of social theory which is actually composed by empirical research (Glaser & Strauss, 1967, p. 6). They stressed the need to generate theory which arises from (and accurately corresponds to) social research which they believed would be "more successful than theories logically deduced from a priori assumptions" (Glaser & Strauss, 1967, p. 6). Glaser and Strauss contended that marrying theory construction with social research would produce a robust and astute hypothesis *grounded* in research. Consequently, Glaser and Strauss fashioned a pioneering methodology to address these issues and bridge the "embarrassing gap between theory and empirical research" (Glaser & Strauss, 1967, p. 2).

Glaser and Strauss entitled their innovative methodology *grounded theory* to encapsulate its overarching objective to ground theory in empirical research. Glaser later abbreviated grounded theory as GT (Glaser & Holton, 2004). This acronym's will be utilised for the duration of this article. Glaser and Strauss reiterated that the ambition of GT is not verification of a preconceived theory, or capacious description, rather it is unambiguously defined by its exclusive endeavour to *discover* an underlying theory arising from the systematic analysis of data. Accordingly, the researcher arrives at a hypothesis (in the form of a theory) at the conclusion of the research which conceptualises the chief concern of the study. To achieve this objective Glaser and Strauss insisted that the researcher must approach the study inductively, with no preconceptions to prove or disprove, in order to uncover (and ultimately conceptualise) the principal concern of participants. The methodology stipulated that the researcher should not know (or predict) in advance where the unfolding research will lead or what the concluding hypothesis would encompass. Strauss later suggested that there was also (to a lesser extent) a deductive component to grounded theory, as during the latter stages of the research the theory would also be systematically verified against the data (Strauss & Corbin, 1990). However, the emphasis was nevertheless chiefly inductive. Thus, GT represented a significant departure from "previous books on methods of social research" as it encompassed an inductive approach to research with the goal of conceptualisation, rather than a deductive approach to a study with the objective of verification (Glaser & Strauss, 1967, p. 1).

Glaser and Strauss designed a number of distinct methodological techniques unique to GT. They stipulated that data collection and analysis occur simultaneously and should be conducted through the specific procedures of *theoretical sampling, coding, constant comparison, saturation and memo writing* (unfortunately there is not the scope in this article to explore these conceptualisations). Glaser and Strauss designed these exacting techniques to ensure that as data is collected, coded, compared, and organised into increasingly abstract categories, a budding theory will begin to emerge. This incipient theory is edited and refined by incoming raw data, to forge a reciprocal relationship between data and theory formation. This approach ensures that the increasing abstraction of concepts is unequivocally substantiated and grounded in the research itself. Therefore, Glaser and Strauss contended that GT successfully marries theory and research as it systematically *discovers* a theory within the substance of the systematic research (Glaser and Strauss, 1967).

Glaser and Strauss asserted the value of this innovative methodology. They argued that during the process of generating a theory, not only do the concepts and hypothesis directly emerge from the data, but they have also been systematically refined by it. They also contended that because the theory has been carefully extrapolated from the empirical research, it generally cannot be repudiated by more data, or superseded with a negating theory, as "it is too intimately linked to data" (Glaser & Strauss, 1967, p. 4). As a consequence, they argued that "despite its inevitable modification and reformulation" over time, a GT is "destined to last" (Glaser & Strauss, 1967, p. 4). Thus, Glaser and Strauss averred the potential and proficiency of their

methodology, insisting that "grounded theories – which take hard study of much data – are worth the precious time and focus of all of us in our research, study and teaching" (Glaser & Strauss, 1967, p. 4).

GT soon began to transcend the immediate context it was created from. Two years after the publication of the *Awareness of Dying* study (1965), Glaser and Strauss (upon request) published *The Discovery of Grounded Theory* (1967) to illuminate the GT methodology they had designed and employed during their research (Glaser, 2002). This text defined and demarcated the rigorous methodology and provided a GT handbook to guide aspiring researchers. Glaser and Strauss published a further two GT studies, *Time for Dying* (1968), and *Status Passage* (1971), and concurrently taught continuing qualitative research seminars, explicating GT, to graduate students at University of California, San Francisco (Strauss & Corbin, 1994). Significantly, many of these students (one of whom was Kathy Charmaz) proceeded to undertake and publish their successive research with a GT framework and thereby disseminate the methodology. By 1970 Glaser founded his own non-profit publishing house, the sociology press, and later moved on from the university to pursue writing, publishing, consulting and teaching internationally (Birks & Mills, 2011). Meanwhile, Strauss remained in UCSF until his retirement in 1987, but continued as an Emeritus Professor (with an enduring commitment to research) until his death in 1996. Significantly, although their lives diverged, both Glaser and Strauss remained strongly committed to the GT methodology they had fashioned.

However, GT did not meet immediate acclaim in the wider academic arena. Strauss retrospectively observed that during the 1960s, the decade in which GT emerged, qualitative research "had sunk to a low status" even among sociologists, as it was deemed incapable of providing verification (Strauss & Corbin, 1994, p. 275). Subsequent sociologists concur, and attest that at that time qualitative research was depreciated and disparaged to the extent that it was considered to be "impressionistic, anecdotal, unsystematic and biased" (Charmaz, 2006, p. 5). As a consequence, erudite quantitative and positivist methodologies became preeminent in the USA and the social science "discipline marched toward defining research in quantitative terms" (Charmaz, 2006, p. 4). Strauss observed that within this climate it took approximately two decades for GT to rise in the estimation of their contemporary American sociologists and to begin to be appreciated (Strauss & Corbin, 1994).

Strauss attributed this slow conversion to the increasing number of books, journals, and papers either employing GT, or disseminating its methodology. He argued that collectively this literature served to illustrate the rigorous and systematic procedures of GT, prove the value of the methodology, and portray GT as visible and accessible to the academic world (Strauss & Corbin, 1994). Significantly, as GT grew in acclaim, it also transcended the discipline of sociology to the extent that it is now utilised by academics from a host of disciplines including speech and hearing sciences (Skeat & Perry, 2008), nursing (Ghezeljeh & Emami, 2009), psychology (Fassinger, 2005), medicine (Bhandari et al, 2003), cinematography (Jones & Alony, 2011), business (Goulding, 1999), information systems (Urquhart et al, 2010), social work (Gilgun, 1994), religion (Gottheil & Groth-Marnat, 2011), anthropology (Strauss & Corbin, 1994) and education (Strauss & Corbin, 1994).

The emergence of GT was seminal to the development of qualitative research, particularly at a time when qualitative research was disparaged. Charmaz insisted that *The Discovery of Grounded Theory* (1967) "made a cutting-edge statement" as it critiqued the prevailing methodological assumptions and pioneered a systematic procedure for qualitative research (Charmaz, 2006, p. 5). Glaser and Strauss proved that qualitative analysis could be methodical, rigorous, and structured (Charmaz, 2006, p. 5). They also demonstrated the compelling logic and potent capacity of qualitative research to generate theories intimately connected with data (Charmaz, 2006, p. 5). Consequently, Charmaz confirms that the

epistemological challenge embedded within GT "transformed methodological debates and inspired generations of qualitative researchers" (Charmaz, 2006, p. 7).

The Great Schism

As Glaser and Strauss continued to mature GT, their progression precipitated professional and methodological divergence. In the 1970's and 80's Glaser and Strauss each wrote a further exposition of GT, but published their books separately rather than collaboratively (Glaser, 1978; Strauss, 1987). By 1990 Strauss had forged an academic alliance with Juliet Corbin and together they refined particular features of the original (Classic) GT. Strauss and Corbin revised the original precept of a natural emergence of a theory from data, to be *discovered* by the researcher. Instead, they devised a highly analytical and prescriptive framework for coding, designed to deduce theory from data systematically (there is not the scope in this article to explore this). This rigorous and meticulous coding framework was underlined by the philosophy of pragmatism and symbolic interactionism. Although there was certainly a nuance of this philosophical inclination embedded within the original configuration of GT (due to Strauss' influence), it was patently more significant and seminal in Strauss and Corbin's reconfiguration of GT. Strauss and Corbin also challenged the tenet of abstaining from literature prior to embarking on the study, highlighting the difference between an "open mind" versus an "empty mind" (Jones & Alony, 2011, p. 99). Consequently, this transformation of the original tenets of GT fashioned the alternative *Straussian GT* which Strauss and Corbin assembled in their book, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (1990).

Glaser criticized Strauss and Corbin's reconfiguration of GT. While the *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (1990) was still pending publication, Glaser wrote (and later published) two personal letters to Strauss articulating his disapproval. Glaser reproached Strauss in these letters stating "your work is fractured and scattered", it "distorts and misconceives grounded theory, while engaging in a gross neglect of 90% of its important ideas" (Glaser, 1992, p. 2). Glaser protested, "you wrote a whole different method, so why call it 'grounded theory'?" (Glaser, 1992, p. 2). Glaser contested that "it indicates that you truly have never grasped what we did, nor studied it to try to carefully extend it" (Glaser, 1992, p. 2). Significantly, Glaser's reproach extended beyond a criticism of Strauss' work, and culminated into a call for action:

> Therefore I demand that you withdraw the book pending a rewriting of it. And then you and I sit down and go through each page of the book and iron out what I consider to be the misconceptions and then rewrite the book by mutual consent. (Glaser, 1992, p. 1)

However, Strauss and Corbin remained steadfast in their position and did not withdraw their reconfiguration of GT. They proceeded with the publication of *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (1990). In contrast to Glaser's rejoinder, they dedicated their book "to Barney Glaser with admiration and appreciation" (Strauss & Corbin, 1990, preface).

Glaser criticised that "Strauss' book is without conscience, bordering on immorality" (Glaser, 1992, p. 5). He counteracted their publication by writing a contending book titled *Basics of Grounded Theory Analysis: Emergence vs. Forcing* (1992). Glaser deliberately structured his book in the "exact chapter sequence and nomenclature" of Strauss and Corbin's *Basics of Qualitative Research* (1990) to specifically enable the reader to "follow the correlation and divergence" between both books (Glaser, 1992, p. 10). He also published his

aforementioned personal letters to Strauss in the preface of his book. Glaser believed "it is up to me to write a cogent, clear correction to set researchers using grounded theory on a correct path" to combat the "wrong ideas", "errors", and "misconceptions" that Strauss and Corbin's book was propagating (Glaser, 1992, p. 3). Thus, Glaser described his publication as "a corrected version of Strauss' book" and he saw himself as the defender of the original GT (Glaser, 1992, p. 3).

In successive years, Glaser, Strauss and Corbin continued to develop their diverging positions. Strauss and Corbin (1990, 1994) published a select few articles disseminating *Straussian* GT. Furthermore, in response to the affirmative feedback from their initial publication, Strauss and Corbin (upon request) published a second edition of *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* in 1998, and a third edition in 2008. Sadly, Strauss had passed away in 1996, two years before the publication of the second edition. However, Corbin wrote in the preface that "although Anselm died before this book was complete, its writing truly has been a collaborative effort" (Strauss & Corbin, 1998, preface). By the third edition, Corbin was careful to incorporate Strauss' voice and distinguished specific sections which Strauss may not have been in accord with. Meanwhile, Glaser published copious books and articles defending and developing the original conception of GT, later identified as *Classic* GT, or *Glaserian* GT (1991, 1998, 2001, 2005). Having already established his own publishing house (Sociology Press), Glaser now launched his own non-profit website and organisation (Grounded Theory Institute), as well as a pertaining journal (*Grounded Theory Review: An International Journal*). He sought to propagate what he deemed to be the pure, authentic, and classic GT; to augment his position he expounded and developed many of the original tenets, including *theoretical sampling, theoretical coding* and *theoretical memos* (Hunter *et al,* 2010; Moore, 2009). As a consequence, Classic GT grew in clarity with successive publications, particularly as Glaser was defending, developing and defining it against *Straussian* GT (and other subsequent reconfigurations). Significantly, despite the contentious schism between these two factions of GT, Glaser and Strauss' personal friendship and professional affinity prevailed until Strauss' death in 1996 (Birks & Mills, 2011).

However, the reformation of GT did not cease with Strauss' death. Neither did the schism remain within the dual confines of Classic versus Straussian GT. An alumni doctoral student from the sociology department of UCSF, Kathy Charmaz, engaged the academic debate and intrepidly fashioned a third variation of GT. Thus, she forged a new chapter within the history of GT.

The Constructivist Controversy

Charmaz enjoyed a unique introduction to GT as she learned it personally from both Barney Glaser and Anselm Strauss themselves. Charmaz was among the first group of doctoral students in the newly established doctoral programme in sociology in the University of California, San Francisco (UCSF), which was instituted and chaired by Anselm Strauss. She recounts Strauss' swift and eager response to her work, articulating that Strauss followed her work "from their first day of meeting until his death in 1996" (Charmaz, 2006, p.vi). Interestingly, Strauss and Corbin even referenced three of Charmaz's grounded theory studies (1980, 1983, 1990) in the bibliography of an article they published in 1994 (Strauss & Corbin, 1994). Charmaz also described that she was taught GT by Barney Glaser, who at the time gave frequent seminars to graduate students at UCSF. She recalls positive experiences, describing that Glaser's workshops "sparked with excitement and enthusiasm" (Charmaz, 2006, p. xii). Thus, she acknowledges that "my journey with GT began with Barney Glaser and Anselm Strauss, whose lasting influence has not only permeated my work, but also my consciousness" (Charmaz, 2006, p. xiii).

However, Charmaz was influenced rather than restricted by Strauss and Glaser. Charmaz described that she responded to Glaser and Strauss' invitation in *The Discovery of Grounded Theory* (1967) to employ GT flexibly in the researcher's own fashion (Charmaz, 2006, p. 9). She accepted this proposal by taking the original tenets of GT and translating them into contemporary research paradigms which had evolved significantly since the conception of GT four decades previously (Charmaz, 2006). In particular she concentrated on interpreting GT within a constructivist paradigm to forge a distinctly Constructivist GT. Thus, Charmaz fashioned a third variation of the GT methodology which she propagated in a number of publications including *Grounded Theory: Objectivist and Constructivist Methods* (2000); *Constructing Grounded Theory* (2006); *Grounded Theory as an Emergent Method* (2008a); *Constructionism and the Grounded Theory Method* (2008b); *Shifting the Grounds: Constructivist Grounded Theory Methods* (2009).

Charmaz's constructivist "interpretation" of GT reconfigured many of its instructions and assumptions (Charmaz, 2006, p. xi). In particular, she rejected Glaser's underlying philosophy of *discovering* an implicit theory. She proposed that "neither the data nor the theories are discovered" and insisted that "we construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices" (Charmaz, 2006, p. 10). Charmaz also diverged from the "methodological rules, recipes, and requirements" of Strauss' highly systematic coding process perceiving it to be overly-prescriptive (Charmaz, 2006, p. 9). Instead she proposed flexible "guidelines" which would "raise questions and outline strategies to indicate possible routes to take" (Charmaz, 2006, p. xi). Thus she departed significantly from both Classic and Straussian *GT*, resisting both Glaser's underlined philosophy and Strauss' prescribed coding process.

Charmaz's rendition of GT provoked an unequivocal response. Glaser responded in his article titled *Constructivist Grounded Theory? (2002)*, describing Charmaz's reconstruction as a "misnomer" (2002, p. 1). Glaser rejected many of the underlining principles of the constructivist paradigm but in particular protested against Charmaz's emphasis on descriptive capture which he depicted as contrary to the goal of conceptualisation within GT. He asserted that Charmaz's reconfiguration lacks the distinctive properties of abstraction, conceptualisation, and systematic theory generation inherent within "pure" GT (Glaser, 2002, p. 13). Glaser also criticized that her depiction of GT procedures such as coding, delimiting, and sampling are "missed, neglected or quashed", averring that she employed these theorising tools to fashion description rather than abstraction (Glaser, 2002, p. 3). He concluded that Charmaz has configured "at best conceptual description, under the guise of calling it Constructivist GT" and contended that "Charmaz talks the talk of conceptualisation, but actually walks the talk of descriptive capture" (Glaser, 2002, p. 3). Thus, Glaser concluded that Charmaz "is misled in thinking that the constructivist vision is in fact GT" at all (Glaser, 2002, para. 40).

However, Glaser's criticisms were directly challenged. Anthony Bryant responded to Glaser's rejoinder by publishing a journal article entitled *A Constructive/ist Response to Glaser* (2003). He outlined his disapproval at Glaser's comments, arguing that Glaser provides "very little to counter or clarify the arguments put forward by Charmaz" (Bryant, 2003, para. 23). Bryant reinforced Charmaz's position, arguing that the GT researcher cannot be rendered an impartial observer, as they inevitably yield an interpretive influence over their analysis, and actively *construct* rather than neutrally *discover* a GT. Bryant defended Charmaz, arguing that her reformation is not only a valid reading of GT, but it is "far more potent and coherent" than Classic GT and "rescues the key ideas of the method" (Bryant, 2003, para. 25). He concluded that while Glaser may have a "certain right" to "feel proprietorial" about his methodology, he

nevertheless "has to acknowledge that GTM[1] has outgrown his grasp" as there are other valid interpretations of GT (Bryant, 2003, para. 25).

In contrast to Glaser's disapproval of reconfiguring GT, Strauss and Corbin embraced its potential. Although, Strauss died in 1996, prior to the birth of Constructivist GT, he (and Corbin) had affirmed that GT should "change with the times" and be attuned to "contemporary intellectual trends and movements" (Strauss & Corbin, 1994, p. 276). They identified a host of potential influences including ethnomethodology, critical theory, feminism, and postmodernism (Strauss & Corbin, 1994). Both Strauss and Corbin welcomed this potential adaptation, reasoning that "no inventor has permanent possession of the invention – certainly not even of its name – and furthermore we would not wish to do so" (Strauss & Corbin, 1994, p. 283). Importantly, Charmaz avowed that while Strauss clearly held a different philosophical perspective, and would have disagreed with many of her ideas, she hopes he would have found them stimulating (Charmaz, 2006)

After Strauss' death, Corbin responded specifically to the constructivist conception of GT and affirmed Charmaz's position so wholeheartedly that she disclosed her personal acquiescence with the paradigm (Corbin & Strauss, 2008). However, Corbin was careful to clarify that Strauss may not have been in accord with this assertion (Corbin & Strauss, 2008).. Significantly, the evolution of GT has certainly not ceased, particularly as Charmaz, Bryant, Corbin, and Glaser continue to publish material. Therefore, the history of GT continues to unfold.

Conclusion

Although this history of GT documents the schismatic nature of the three variations of GT, it is important to recognise that they nevertheless retain some familial resemblance. Despite Glaser's protestations, Straussian and Constructivist GT still claim a kinship with the original Classic GT. Indeed Straussian and Constructivist grounded theorists continue to embrace a number of the original innovative methodological techniques (including theoretical sampling, saturation, the constant comparison and memo writing) which originated in *The Discovery of Grounded Theory* (1967). As a consequence, although Classic, Straussian, and Constructivist GT, are undoubtedly distinct and diverging variations of GT, they nevertheless remain within the GT family albeit with some heated family arguments.

A post-script from the authors

There was not the scope in this article to examine the methodological or philosophical directives that distinguish the three factions of GT. However the authors' accompanying article, "Contrasting Classic, Straussian and Constructivist Grounded Theory: Methodological and Philosophical Conflicts", examines this subject.

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Author Note

Méabh Kenny is a PhD student under the supervision of Dr. Robert Fourie in University College Cork (UCC), Ireland. Méabh has a background in Social Work and her PhD is entitled: *A qualitative analysis of parental coping following early diagnosis of hearing loss in Ireland.* Méabh has selected Straussian Grounded Theory as her chosen methodology for this research. In the same way that the classical composer Johann Sebastian Bach inscribed SDG (an acronym for *Sola Dei Gloria)* at the end of his manuscripts, Meabh works with the aspiration that her work would sing the same praise. Correspondence regarding this manuscript can be addressed directly to: Méabh Kenny at the following: Email: meabh.kenny@gmail.com; Address: Dept. of Speech and Hearing Sciences, Faculty of Medicine and Health, Brookfield Health Sciences Complex, University College Cork, College Road, Co. Cork, Ireland, Europe.

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ii. Second Published Journal Article (published after this study was defended)

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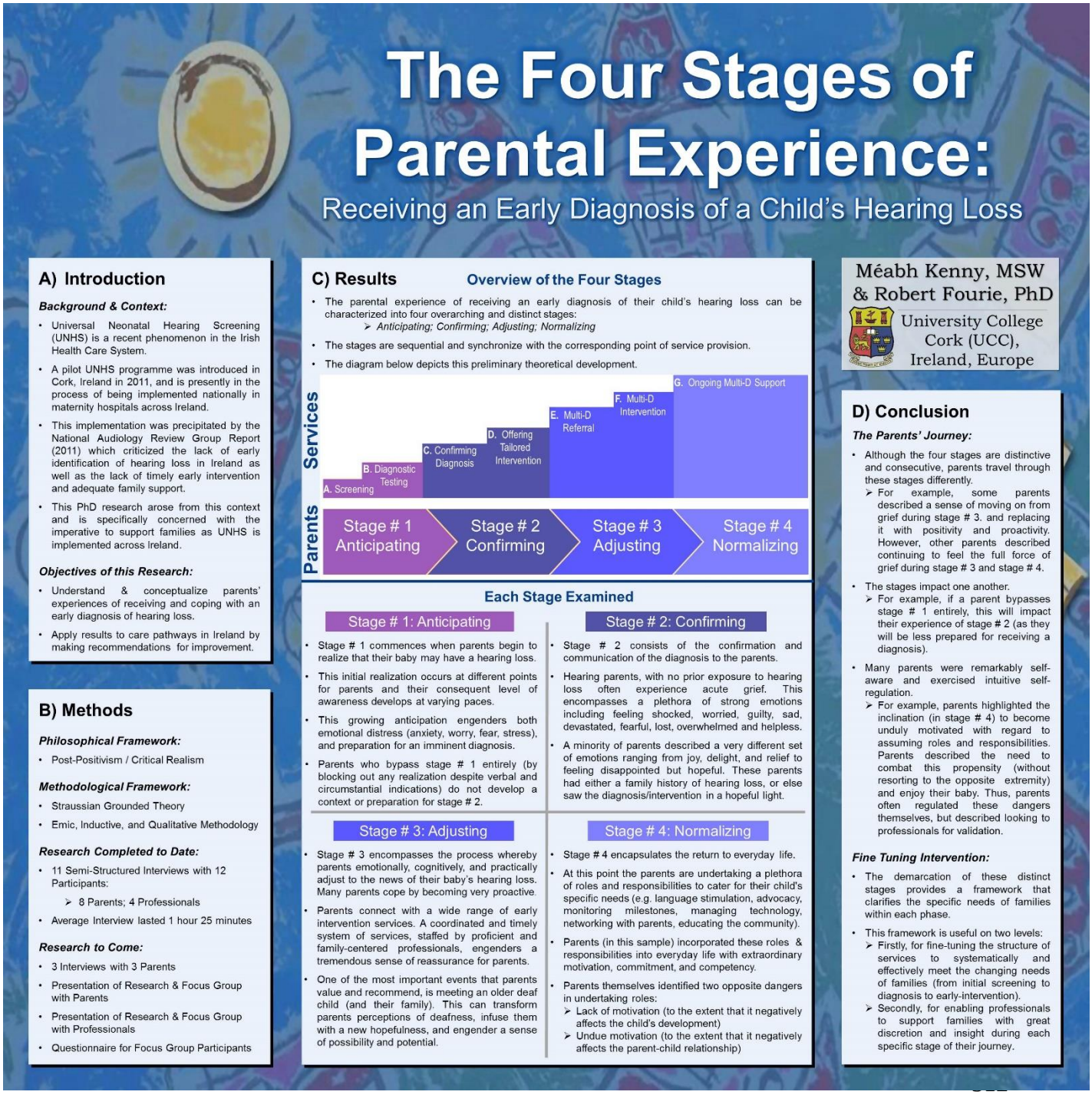
iii. Poster Presented at EHDI (Early Hearing Detection and Intervention) Conference in USA (April 2014)



iv. Feedback from Poster Presentation at EHDI (Early Hearing Detection and Intervention) Conference (April 2014)

The Four Stages of Parental Experience: Receiving a Diagnosis of a Child's Hearing Loss (n=4) Presented by Meabh Kenny, Dr. Robert Fourie **(1=poor; 5=excellent)**	Average	St Dev
Overall quality of Poster presentation	5.00	0.57
Organization / clarity of the Poster	5.00	0.57
Presentation (how well the presenter conveyed info during the session)	5.00	0.57
Usefulness of information	5.00	0.50
Relevance of topic	5.00	0.50
Adequate opportunity to interact/engage with presenter(s)	5.00	0.57
Usefulness of handouts / support materials	5.00	

Overall Poster Evaluations (n=164) **(1=poor; 5=excellent)**	Average	St Dev
Overall quality of Poster presentation	4.58	0.58
Organization / clarity of the Poster	4.57	0.63
Presentation (how well the presenter conveyed info during the session)	4.56	0.61
Usefulness of information	4.59	0.57
Relevance of topic	4.67	0.56
Adequate opportunity to interact/engage with presenter(s)	4.39	0.96
Usefulness of handouts / support materials	4.67	0.61

Groups Represented	
Advocacy Group	1
Audiologist	92
Early Intervention Provider	38
Family of a Child with Hearing Loss	7
Federal Agency	6
Hospital/Birthing Center	5
Local Health Dept.	0
Medical Provider	7
Non-Profit Agency	5
Part C Agency/Provider	25
State Education System	11
State Health Dept.	49
Student	5
University	23
EHDI Coordinator	26
Other…	32

v. Additional Resources Created During this Study

The researcher also created two podcast lectures for the UCC Research Methodology module CT6000. These podcasts each run for the duration of one hour, and are entitled:

1) Analysing Textual Data
2) Using Software for Textual Analysis

These lectures are audio-visual, with pictorial demonstration of how to code data and employ software.

S.D.G.