<table>
<thead>
<tr>
<th>Title</th>
<th>Parents' experiences of child growth and development concerns: an interpretative phenomenological analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author(s)</td>
<td>Mulcahy, Helen</td>
</tr>
<tr>
<td>Publication date</td>
<td>2014</td>
</tr>
<tr>
<td>Type of publication</td>
<td>Doctoral thesis</td>
</tr>
<tr>
<td>Rights</td>
<td>© 2014, Helen Mulcahy. <a href="http://creativecommons.org/licenses/by-nc-nd/3.0/">http://creativecommons.org/licenses/by-nc-nd/3.0/</a></td>
</tr>
<tr>
<td>Item downloaded from</td>
<td><a href="http://hdl.handle.net/10468/1977">http://hdl.handle.net/10468/1977</a></td>
</tr>
</tbody>
</table>

Downloaded on 2020-01-02T11:54:22Z
Parents’ experiences of child growth and development concerns:
An Interpretative Phenomenological Analysis

Helen Mulcahy
95200207

March 2014

This thesis is submitted for a Doctor of Nursing Degree from
The National University of Ireland, Cork
University College Cork
Catherine McAuley School of Nursing and Midwifery

Supervisors
Professor Eileen Savage, Chair of Nursing and Head of School of Nursing and Midwifery, UCC.
Dr Rhona O’Connell, (Co-supervisor) School of Nursing and Midwifery, UCC
# Table of Contents

Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table of Contents</td>
<td>i</td>
</tr>
<tr>
<td>Tables</td>
<td>iv</td>
</tr>
<tr>
<td>Figures</td>
<td>iv</td>
</tr>
<tr>
<td>Appendices</td>
<td>iv</td>
</tr>
<tr>
<td>Declaration</td>
<td>v</td>
</tr>
<tr>
<td>Abstract</td>
<td>vi</td>
</tr>
<tr>
<td>Dedication</td>
<td>vii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>viii</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Chapter 1: Background to child growth and development</td>
<td>6</td>
</tr>
<tr>
<td>Prevalence of developmental delay and disorders</td>
<td>9</td>
</tr>
<tr>
<td>Consequences of growth and developmental delay</td>
<td>10</td>
</tr>
<tr>
<td>Managing growth and developmental delay</td>
<td>11</td>
</tr>
<tr>
<td>Chapter 2: Empirical and conceptual literature review</td>
<td>16</td>
</tr>
<tr>
<td>Introduction</td>
<td>16</td>
</tr>
<tr>
<td>Search strategy</td>
<td>16</td>
</tr>
<tr>
<td>Empirical perspectives of parental concern</td>
<td>17</td>
</tr>
<tr>
<td>Source of parents’ concerns</td>
<td>17</td>
</tr>
<tr>
<td>Timing of the onset of parental concern</td>
<td>24</td>
</tr>
<tr>
<td>Parents perceptions about child growth and development</td>
<td>28</td>
</tr>
<tr>
<td>Parents’ experiences of seeking help and expressing a concern</td>
<td>36</td>
</tr>
<tr>
<td>HCPs’ practices in eliciting and attending to parental concern</td>
<td>46</td>
</tr>
<tr>
<td>Conceptual and theoretical perspectives on parental concern</td>
<td>56</td>
</tr>
<tr>
<td>Uncertainty in Illness Theory</td>
<td>56</td>
</tr>
<tr>
<td>Lay Knowledge</td>
<td>59</td>
</tr>
<tr>
<td>Help-Seeking behaviour</td>
<td>62</td>
</tr>
<tr>
<td>Summary and conclusion</td>
<td>64</td>
</tr>
<tr>
<td>Chapter 3: Methodology and methods</td>
<td>67</td>
</tr>
<tr>
<td>Aim</td>
<td>67</td>
</tr>
<tr>
<td>Definition of terms</td>
<td>67</td>
</tr>
<tr>
<td>Research design</td>
<td>68</td>
</tr>
</tbody>
</table>
Ontological and epistemological stance 69
Phenomenological considerations 72
Interpretative Phenomenological Analysis (IPA) 74

Study Sample 76
Access and recruitment of participants 78
Data collection procedures 80
Ethical considerations 83
Analytical techniques 84
Methodological rigour 89
  Reflexivity 94

Summary 96

Chapter 4: Findings 98

Characteristics of sample 98
  Edwina 101
  Denise 101
  Gina 102
  Noelle 102
  Sonya 102
  Pattie 103
  Connie 103
  Muriel 103
  Jack 104
  Meg 104
  Kim 104
  Ella 105
  Antony and Donna 105
  Felicity 105
  Siobhán 106

Background context 106
  The concern – ’telling it as it is’ 106
Referred on 110
  The process of referral 111
Waiting for the outcome

**Superordinate themes**

*Uncertainty “a little bit not sure”*

Appraising the concern

Watching for a while

Making comparisons – “Barometer”

Assessing child doing other things

Puzzling– “Is there something wrong?”

Wondering about the cause

*Parental knowledge – ‘Being and getting in the know’*

‘Being in the know’

Seeking information – “just Google”

**Triggers to action**

Usual disposition – to panic or not to panic

Seeking affirmation from family

Seeing the child’s vulnerability

Impact on the child

Others noticing the problem

Time passing

*Getting child’s problem checked out*

Just check it out

Better safe than sorry

Concern mentioned in passing

Getting into the health system, public or private

In the hands of the professionals

Professional validation

Therapeutic relationships

**Summary**

**Chapter 5: Discussion**

*Experiences of ‘The Concern – telling it as it is’ and being ‘Referred on’*

*Uncertainty – ‘a little bit not sure’*

*Parental Knowledge – ‘being and getting in the know’*
Triggers to action 171
Getting the child’s problem checked out 177
Strengths and Limitations 187

Conclusion 189
Recommendations 192
References 196
Appendices 210

Tables
Table 3.1 Adherence of study to methodological rigour .............................................91
Table 4.1 Biographical and relevant details of parents and children of concern ........100

Figures
Figure 3.1 Diagrammatic representation of IPA analysis steps ..................................87
Figure 4.1 Diagrammatic representation of themes ....................................................115

Appendices
Appendix 1. Written permission from DPHNs to access clinical sites ......................211
Appendix 2 Ethical approval .....................................................................................212
Appendix 3. Cover letter to potential participants ....................................................213
Appendix 4. Study Information Leaflet for Parents. .................................................214
Appendix 5. Consent by subject for participation in research protocol ..................215
Appendix 6 Interview Schedule .............................................................................217
Appendix 7 Convention for transcription of audio files. ........................................218
Appendix 8 Wordle of Muriel’s transcript ...............................................................219
Appendix 9 Gantt chart ...........................................................................................220
Appendix 10 Screenshot of analysis log from NVivo ..............................................221
Appendix 11 Screenshot from NVivo 26th May 2013 ..............................................222
Appendix 12 Table of themes for Uncertainty – “a little bit not sure” .........................223
Appendix 13 Table of themes for Parental Knowledge – Being and Getting in the know 224
Appendix 14 Table of themes for Triggers to action .............................................225
Appendix 15 Table of themes for Getting child’s problem checked out ................226
Declaration

I declare that while registered for the degree of Doctor of Nursing (DN)
I have not been a registered candidate or enrolled student of any other award
at another academic or professional institution

Helen Mulcahy
95200207

I declare that the content of this thesis is all my own work. Where the work of
others has been used to augment it has been acknowledged and/or referenced
accordingly.

Signed ____________________________

Date______________________________
Abstract

**Background:** Assessing child growth and development is complex. Delayed identification of growth or developmental problems in children until school entry has health, educational and social consequences for children and their families. Health care professionals (HCPs), including Public Health Nurses (PHNs) work with parents to elicit and attend to their growth and development concerns. It is known that parents have concerns about their children’s growth and development which are not expressed to HCPs in a timely manner. Measuring parental concern has not been fully effective to date and little is known about parents’ experiences of expressing concern about their child’s growth and development.

**Aim:** To understand how parents make sense of child growth or development concerns.

**Method:** The study was qualitative using Interpretative Phenomenological Analysis (IPA). A purposeful sample of 15 parents of pre-school children referred by their PHN to second tier services was used. Data were collected by semi-structured interviews which were audiotaped and transcribed. NVivo version 10 was used for data management purposes. Data were analysed using IPA.

**Findings:** Findings yielded two contextual themes which captured how parents described *The Concern* – ‘telling it as it is’ and their experiences of being *Referred on*. Four superordinate themes were found which encapsulated the *Uncertainty* – ‘a little bit not sure’ of parents as they made sense of the child’s growth and development problems. They were influenced by *Parental Knowledge* – ‘being and getting in the know’ which aided their sense-making before being prompted by *Triggers to action*. Parents then described *Getting the child’s problem checked out* as they went to express their concerns to HCPs.

**Conclusion and Implications:** Parental expression of concerns about their child is a complex process that may not be readily understood by HCPs. A key implication of findings is to reappraise how parental concern is elicited and attended to in order to promote early referral and intervention of children who may have growth and development problems.
Dedication

To Ann,

My anam cara
Acknowledgements

I would like to thank my supervisor Professor Eileen Savage, whose expertise in qualitative research and child health assisted, supported and guided me through to the completion of this study.

To my co-supervisor Dr Rhona O’Connell, thank you for your guidance and support.

To Professor Geraldine McCarthy, your inspiration at each step of my academic journey started back in 1994 and I thank you for it.

I would like to thank my fellow doctoral student colleagues. It was encouraging and reassuring to undertake this journey together.

Thanks to all the Public Health Nurses in HSE South who assisted in any way either through helping me access the sample of parents or by being generally supportive.

To my parents Joe and Edith thank you for always being so understanding, encouraging and supportive.

I would like to thank my family, friends and colleagues for tolerating my absence, distractibility and general grumpiness over the last three years. I promise to make up for it.

To my partner Ann who was there from the very beginning of this doctorate journey. Your love and support kept me mentally and physically healthy, by being with me, never doubting me and reminding me about the light at the end of the tunnel. I got to this point because of you.

Finally I would like to thank all the parents who gave of their time to take part in this study and who shared so much of their personal experiences. It would not have been possible without them and I will do as much as I can to ensure their voices are heard widely and make a difference.
Introduction

The total population of pre-school children in Ireland is 356,329, representing 7.76% of the population (Central Statistics Office 2011). As a consequence, preventative child health services in Ireland are very important to the nation’s health. These services are organised and delivered through a programme of Child Health Screening, Surveillance and Health Promotion (CHSSHP). This universal service to all children and their families is provided from birth to the end of the school-going period. In line with international best evidence this programme was reoriented in recent years (Denyer et al. 1999, Health Service Executive 2005a) from one focused on developmental screening to a Developmental Surveillance (DS) model. DS is defined as:

“a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care. The components of developmental surveillance include eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informed observations of children and sharing opinions and concerns ...”(Dworkin 1989 p.1001).

The main purpose of DS is to assess child growth and development so that deviations from the norm, which may indicate developmental delay, developmental disorders or growth disorders, are identified as early as possible. While growth or developmental delay may not be permanent, it can be the basis or marker for subsequent growth or developmental disorders. Among these are autism, cerebral palsy, speech and language disorders, intellectual or learning disabilities, hearing or vision impairment or growth disorders such as failure to thrive (FTT) (Lü et al. 2011, Olsen et al. 2007, Sices 2007, WHO and UNICEF 2012).

Child development is defined “as the processes underlying the change in growth and
capability in the child” (Empson and Nabuzoka 2004 p. 36). Assessing child
development is vitally important because it is a critical indicator of health. Between
5% and 18% of children have some form of developmental delay, disorder or
disability (Center for Disease Control and Prevention 2013, Health Service Executive
2005b, NICE 2012, Shevell et al. 2001, Sices 2007, Simpson et al. 2003, WHO and
UNICEF 2012). Only 30% to 50% (Glascoe 2001, Glascoe et al. 2006, Sand et al.
2005) of developmental/behavioural disabilities are identified before going to school.
The optimum period for early intervention is in the pre-school period (Sices 2007).
This means a sizeable proportion of children are starting school with unidentified
growth and developmental delays which can affect their health, educational and
social well-being as well as causing distress and worry for their families (NICE
2012). It also means undiagnosed developmental problems are of great public health
significance. As effective developmental surveillance hinges on eliciting and
attending to parental concern it follows that parental concern is of significance to not
only child health at the individual and family level but to population health generally.
The population of interest in this study are pre-school children and their parents.

In Ireland the CHSSHP model has a schedule of seven developmental surveillance
visits, from birth to 11 years, involving Public Health Nurses (PHNs) and parents. It
could be argued that at a very basic level, all the components of developmental
surveillance as defined above cannot occur unless parents and their children engage,
either at home or in clinics with Health Care Professionals (HCPs). Parents are
widely acknowledged as having expert knowledge in judging their own children’s
growth and developmental progress (de Geeter et al. 2002, Department of Health
2009, Health Service Executive 2005a). If this is not to be perceived as rhetoric, they
have a major role in recognising any growth and development problems. Working with parents to identify developmental delay is of great importance to public and community health nursing (Hawkins-Walsh and Stone 2004, NICE 2012). In Ireland the training for PHNs and Public Health Doctors stresses working with parents and eliciting and attending to parental concern about child growth and development at every therapeutic opportunity (HSE 2005). However, this is not always prioritised in countries where there is an absence of health care governance to manage infant developmental needs (Leech et al. 2007). Child health services in other countries such as the United Kingdom (UK) and United States of America (USA) have been recently reviewed (American Academy of Pediatrics 2008, Department of Health 2009). Addressing the deficits in the healthcare needs of children in Ireland requires “the development of an integrated national programme for child health” underpinned by best available evidence (Kilkelly and Savage 2013 p.49).

Evidence suggests significant under-detection of developmental delay with children not being identified in a timely way (American Academy of Pediatrics 2008, Sand et al. 2005, Sices 2007). This was the initial trigger for interest in exploring and researching this topic in the current study. Delayed identification of developmental delay in children until school entry is a global concern for those who provide preventative child health services. There is a view, mainly from the USA that the solution to the problem of delayed identification of developmental delay lies in improving screening tools for systematic developmental screening1 (Sices 2007, Sices et al. 2008). The main argument stems from the view that paediatricians’ time is limited and there is value in having a parent complete a screening tool such as the

---

1 Developmental screening is defined as “systematic use of a validated screening tool to identify children likely to have a developmental delay, with all children in a practice or population regardless of risk” (Sices 2007 p.18)
Paediatric Symptom Checklist prior to the consultation so that the focus of the discussion can be on the specific issues identified (Glascoe 2002, Hacker et al. 2006). In contrast, preventative efforts based on a developmental surveillance model are favoured in other countries such as the UK and Ireland. Restall and Borton (2010) believe that not enough is known about all potential risk factors of poor developmental outcomes for children to adopt a targeted screening approach. Consequently, universal surveillance is preferred over targeted screening to maximise the potential of identifying children who need additional assessment and access to early intervention. In support of screening, Sices (2007) suggests that any negative consequences such as increased parental anxiety can be addressed. Notably, this is the only mention of parents by Sices (2007) in her recommendations for screening practices at that time in the USA.

Evidence supports HCPs carefully eliciting parental concerns to detect the type and level of concerns raised to allow implementation of the appropriate intervention (Beauchesne et al. 2004). Knowing what will encourage and facilitate parents to express concern about child growth and development, and how they express the concern may facilitate earlier referral to early intervention and may ultimately improve child and parental outcomes (Ellingson et al. 2004, Poon et al. 2010). Therefore, the aim of this study is to understand how parents make sense of child growth or development concerns.

Firstly in chapter one the background context of child growth and development will be described in terms of definitional aspects, the prevalence of growth and development problems, the consequences of child growth and development delay and
managing child growth and development. This chapter will serve to contextualise parental concern.

In chapter two a review of the empirical literature will be undertaken to explore parental concern in the context of child growth and development. The search strategy will be described followed by an evaluation of literature relating to: the source and timing of parental concern; parental perceptions and experiences of concern; and HCP practices in terms of eliciting and attending to parental concern. Also in chapter two conceptual and theoretical literature relating to uncertainty, lay knowledge and help-seeking will be introduced. This literature review chapter will end with a summary and conclusion of the state of knowledge about parental concern.

Chapter three will detail the ontological and epistemological considerations as well as the methodology and methods used in the study. A rationale for the use of Interpretative Phenomenological Analysis (IPA) will be provided along with details relating to sample, access, data collection, ethical considerations, analysis and rigour.

The findings will be presented in chapter four and will be organised according to the characteristics of the sample, the background context and the four superordinate themes. In chapter five the findings will be organised according to the four superordinate themes found and will be discussed in the context of the existing empirical and conceptual literature. The thesis will conclude with a section of strengths and limitations, the final conclusion and implications for education, practice, research and policy.
Chapter 1: Background to child growth and development

Children develop dynamically from infancy to adulthood, from dependency on parents and caregivers through to independence. They grow and develop rapidly, through a series of milestones or steps, often in spurts, in infancy and the preschool years. The acquisition of child development skills in physical, cognitive, behavioural, emotional or social areas follows a normal distribution. However, the pace and variation of normal child growth and development makes assessing child development a complex issue. It has been likened to measuring a ‘moving target’ (Marks et al. 2008). Even experienced clinicians have difficulty assessing normal growth (Wright and Weaver 2007) but especially with identification of subtle developmental problems (SDP)\(^2\) (Caronna et al. 2007, Glascoe 2000b, Poon et al. 2010). Diagnosing physical disabilities like hearing impairment and cerebral palsy were the key questions 30 years ago whereas more subtle problems like autism spectrum disorders (ASD) are seen as the new ‘frontier’ (Caronna et al. 2007). They stated that it is quite challenging for paediatricians to recognise those children who need prompt referral and intervention versus those “for whom ‘watchful waiting’ is appropriate” (Caronna et al. 2007 p.407). However relationships with parents can be strengthened by HCPs acknowledging the uncertainty (Caronna et al. 2007).

Developmental delay is defined as a failure to acquire a particular developmental skill in one or more linked developmental domain (sensory-motor, cognitive, communication and social-emotional) at an age when 95% of peers have done so (Haddad et al. 2000). Alternative definitions of significant developmental delay

---

\(^2\) Subtle Developmental Problems (SDPs) was first used by Williams and Holmes (2004) as an overarching term to describe mild developmental delays and deviations e.g. poor muscle tone, clumsiness, speech delay, behavioural problems and short attention span.
include a discrepancy of 1.5 to two standard deviations from the mean in one domain and global delay in two or more developmental domains (Poon et al. 2010, Sharma 2011). Alternative terms such as Specific Developmental Disorders (SDD) and Pervasive Developmental Disorders (PDD) are also used, with the former being described as delay in one domain and the latter as delay in multiple functions, including communication and socialisation (Rispens and van Yperen 1997, WHO 2010).

In addition to developmental delay, a variety of other diagnostic classifications are used. For example, the International Classification of Diseases and Related Health Problems -10th Revision (ICD-10)(WHO 2010) lists category R62 as ‘lack of expected normal physiological development’ with subcategories of ‘R62.0 delayed milestone’ and ‘R62.8 other lack of expected normal physiological’. The former ‘R62.0 delayed milestone’ is described as including late talkers and late walkers. The latter ‘R62.8 other lack of expected normal physiological’ includes failure to thrive and gain weight, infantilism-not otherwise specified, and ‘lack of growth’ and ‘physical retardation’. While these terms combine growth and development they also reflect that the term ‘delay’ may be insufficient, as there may also be deviations rather than delay to the typical sequence of development. For example, children who have cerebral palsy may roll over earlier than expected because of increased muscle tone or there may be dissociations and regressions (Poon et al. 2010). According to Peterson et al. (1998) the term developmental delay is often used loosely to imply

3 The International Classification of Diseases (ICD) is the standard diagnostic tool for epidemiology, health management and clinical purposes. It was endorsed by all WHO member states. (WHO 2010)

4 Dissociations are widely varying rates of development in different domains e.g. typical gross motor but significant language delay in children with Autism

5 Regression indicates loss of previously acquired developmental skill and is a serious neurological sign. (Poon et al. 2010)
any kind of developmental problem, or temporarily until a child is old enough to be diagnosed with mental retardation⁶. They suggest this may be because the complexity of neurodevelopment in humans precludes the adoption of a single classification system that meets all needs (Petersen et al. 1998). Hence the term developmental delay is widely used in the literature and has a certain accepted resonance with child health researchers despite its aforementioned limitations. The complexity of identifying developmental delay exists because the types of delay can vary and up to one third of referred children have multiple needs potentially indicative of more serious disorders (McKay et al. 2006).

Delay may be a marker or initial sign for more serious disorders such as those categorised in Disorders of Psychological Development in section F80-F89 of the ICD-10 (WHO 2010). These disorders have a number of characteristics in common: their onset is during infancy or childhood; the delay is sharply related to biological development of the central nervous system; and they follow a distinctive course without relapse or remission. Typically, the affected functions include language, motor coordination and visual-spatial skills. Two broad categorisations are evident from the ICD-10 classification, namely Specific Developmental Disorders (SDD) and Pervasive Developmental Disorders (PDD) each of which will be used hereafter where appropriate for ease of understanding. Disorders within the SDD group include specific speech and language disorders; specific developmental disorders of motor function such as childhood coordination disorder and dyspraxia; and specific developmental disorders of scholastic skills such as dyslexia. PDDs include

⁶ Although still used in the literature the term mental retardation has been replaced by intellectual disability.
childhood autism, atypical autism, Asperger’s disease, Rett’s disease, autism-not otherwise specified (NOS) and childhood disintegrative disorder.

**Prevalence of developmental delay and disorders**

According to the WHO and UNICEF (2012), approximately 15% of the world’s population have some form of disability but that it is very difficult to identify precise prevalence estimates because of variety of definitions, changes in disease and disorder classifications and the measurements used. Nevertheless two eminent authors in the field of developmental paediatrics have recently published prevalence figures (Boyle et al. 2011, Fombonne 2009). It is not possible to do direct comparisons as they have used different methods and measures for different conditions. Boyle et al. (2011, 2012) calculated an overall disability prevalence of 13.9 % for non-institutionalized children aged three to 17 years from the household survey conducted by the census bureau on a sample of 119,368 individuals for the Centre of Disease Control (CDC) in the USA. The diagnoses of various SDDs and PDDs came from parent self-reports. The prevalence rate also included ADHD which is not classified as an SDD within the ICD-10 but within a separate hyperkinetic classification. Using a different approach, Fombonne (2009) found the total prevalence figure for PDDs as 63.7/10,000. This came from a review of 43 epidemiological studies from 17 countries in the years 1966-2008. To summarise from the data presented from both sources, 1 in 6 children have a SDD and 1 in 150 children have a PDD. Contrary to popular belief, Fombonne (2009) does not believe there is evidence to support an ‘autism epidemic’ but does accept that there is increasing lay and professional knowledge of ASD and children are now younger at diagnosis.
Consequences of growth and developmental delay

The consequences for the child of delayed growth and development identification and intervention include adverse impact on future academic and social functioning (McKay et al. 2006) and poorer general health status (Hamilton 2006). According to Peterson et al. (1998), outcomes include functional limitations, disabilities and societal limitations depending on the aetiology and pathophysiology of the delay. There can also be poor child psychosocial health (Webster et al. 2008) or educational and behavioural problems (Law et al, 2003).

Withdrawn behaviour, sleep problems and aggressive behaviour in the child are associated with attention problems and have the capacity to cause significant stresses for parents (Tervo 2010). Global developmental or language delay development in children pose multiple parenting challenges including: parenting stress (Baker et al. 2005, Webster et al. 2008) impaired parental mental health and family functioning (Baker et al. 2003, Herring et al. 2006). When measured, mothers were found to experience more stress than fathers (Baker et al. 2005, Herring et al. 2006).

There can also be relatively positive consequences to receiving a diagnosis of developmental disorder. A definitive diagnosis of developmental disorder, albeit distressing for parents can also be seen as a relief, especially after a period of searching, and a starting point for parents to move forward with planning for intervention (Noterdaeme and Hutzelmeyer-Nickels 2010). According to Bailey et al. (2004) earlier identification can put a stop to the ‘diagnostic odyssey’ which entails emotional and financial costs on parents as they pay numerous visits to HCPs seeking validation for growth and development concerns about their children. There
are significant consequences with developmental delays and disabilities for society associated with the on-going provision of health, education and other support services (NICE 2012, Sices 2007). In light of the consequences outlined above for children, families and populations, there is evidence to support developmental delay as an important topic for on-going research.

**Managing growth and developmental delay**

Early detection and diagnosis of growth and development delay leads to early intervention and management. The WHO and UNICEF (2012) recommends a three pronged approach in relation to support and care of children with disabilities which are early identification, assessment and early intervention. Paediatricians, public health doctors, Health Visitors (HV) or PHNs provide child health services depending on the jurisdiction. In Ireland, PHNs, public health doctors and GPs are encouraged to elicit parental concerns at various developmental stages according to the recommendations of the CHSSHP (Health Service Executive 2005a). This is also the case for HVs and others in the UK under the Healthy Child Programme (Department of Health 2009). In the USA paediatricians, Pediatric Nurse Practitioners (PNP), child health nurses are urged to elicit and attend to concerns as part of the Bright Future Guidelines (American Academy of Pediatrics 2008) or other programmes such as Assuring Better Child Health and Development (ABCD) programme in place in a number of states (Wagner et al. 2006).

In the context of the CHSSHP programme in Ireland, the process is operationalised when a child with developmental delay, identified by the parent or PHN is referred to a second tier clinic for assessment and/or diagnosis and further referred to an Early Intervention Team for specific interventions. Second tier clinic is a term first
described by the Health Service Executive (HSE) (2009) to describe a clinic provided by Area Medical Officers (AMOs) to which PHNs can refer any child growth or development issue. The child may then be further referred to an Early Intervention Team for specific coordinated interventions where appropriate. There are differences from one Local Health Office (LHO) to the next in terms of the way these second tier clinics are organised. Referrals to allied health professionals such as Speech and Language Therapists (S&LT), Occupational Therapists (OT), Physiotherapists or Orthoptists for assessment and/or diagnosis may have to go through the second tier clinic or in many areas PHNs can refer directly to them.

Bailey et al. (2004) in the USA described the process of early identification of developmental problems as becoming concerned about the child, investigating the problems and obtaining services. They stated that families and HCPs must discover “the presence of disability by observing the child and making sense of emerging concerns about health, development or behaviour” (p.887). International evidence supports Early Childhood Intervention (ECI)\(^7\) to improve child developmental and social outcomes (Denyer et al. 1999, National Health and Medical Research Council 2007, NICE 2012, Sices 2007, WHO and UNICEF 2012). According to the WHO and UNICEF (2012) the evidence for investing in Early Childhood Development comes from a number of reasons; namely, as a basic human right and also for economic, scientific and programmatic reasons. The WHO and UNICEF (2012) suggest that well designed programmes may assist parents and HCPs to improve child development and detect developmental delays early with consequent population health advantages, providing a programmatic rationale. Promoting optimum

\(^7\) Early Childhood Intervention programmes may be those designed to support children at risk of developmental delay or disability or the specialised services to which young children identified as having a delay may be referred for secondary or tertiary care (WHO and UNICEF 2012)
development increases the likelihood of healthy productive adults and has an economic benefit by saving on future medical, education and social costs. The scientific rationale comes from the nature of child development. The first three years of a child’s life are typified by rapid development, mostly of the brain where the critical foundations of development and growth proceed. ECI is essential in this critical period “if children with disabilities are to survive, flourish, learn, be empowered and participate” (WHO and UNICEF 2012 p.18). Additionally, Bellman and Vijeratnam (2012) signalled that the benefits of developmental surveillance should not only be viewed in terms of the abnormalities detected but also in terms of the opportunities provided to support and reassure parents. For those children who have been diagnosed with a PDD it is important that interventions are not just focused on communication and motor skills but also on a child’s social skills, to minimise the impact on family functioning and parenting stress (Webster et al. 2008).

From my clinical experience as a PHN and from previous research (Mulcahy 2002, 2004), I am aware that those parents who may be most in need or vulnerable in any way are those who may fall through the gaps in service provision. With services being further contracted during periods of recession there is an increased possibility of this happening. Universal preventative child health services make an important contribution to child public health (Bellman and Vijeratnam 2012, Layte 2013). Their universal nature has the benefit of being non-stigmatising and thus has the potential to encourage more effective engagement with parents for them to express concerns (Bidmead and Whittaker 2008, Cowley et al. 2013, Mackintosh 2013). Risk factors such as family poverty, low maternal educational attainment, parents’ mental...
illness, premature birth, suboptimal nutrition and child neglect and abuse increases the likelihood of developmental delays (Sices 2007). Furthermore children most in need of further developmental assessment are less likely to receive it due to poverty or ethnicity (McKay et al. 2006), a feature that has been described as the inverse care law. The inverse care law was first described by Dr Julian Tudor Hart in 1971 and proposes that health care is least available to the people who most need it (Socialist Health Association 2013). Inequalities in child health such as described above are widely acknowledged to be a compelling argument for universal preventative child health programmes (Bellman and Vijeratnam 2012, Blair and Hall 2006, Health Service Executive 2005b, Layte 2013).

In the US where there are many inequalities in child health there have been calls for the American Academy of Paediatrics (AAP) (Council on Children With Disabilities Bright Futures Steering Committee 2006) screening and surveillance algorithm to be revised because it is considered to be focused solely on early detection of developmental delay and referral to early intervention (Marks et al. 2011). A more generalist focus with eliciting and attending to parental concerns about child growth and development is a key element of effective developmental surveillance and is in line with international best practice (Marks et al. 2011). This means that eliciting and attending to parental concerns should be a critical element of the consultation at each of the scheduled developmental assessments as well as at other opportunistic child health encounters. In the UK, changes in service delivery and more targeted services have resulted in greater expectations that parents will come forward with their concerns (Condon 2008). It is known that parents are able to raise concerns about child growth and development at an early stage (Glascoe 2000a, 2003) but that they
are not always encouraged and facilitated to do so by HCPs. They may even be ill-prepared/educated, reluctant or reticent (Sices et al. 2008). They may also lack knowledge or be in denial (De Giacomo and Fombonne 1998). If parents are being expected to be more proactive in expressing concern then it befits researchers to study this area.

The content and timing of the CHSSHP schedule in Ireland has been audited (Health Service Executive 2009) but it is unknown to what extent PHNs elicit and attend to parental concerns or how in fact they do it. Neither have the experiences of parents in expressing a growth or development concern been explored. Much of the literature on developmental surveillance and delay is dominated by paediatric developmental specialists such as Glascoe and nursing literature in relation to eliciting and attending to parental concern is sparse (Williams and Holmes, 2004). This may reflect the fact that primary preventative child health work is carried out mainly by physicians in the USA and mainly nurses in UK and Western Europe. It is timely then that the topic of parental concern be examined in the following chapter using a nursing lens to gain a different insight to the topic.
Chapter 2: Empirical and conceptual literature review

Introduction

This chapter will commence with a description of the search strategy used to source empirical and theoretical literature on parental concern. Empirical literature on parental concern will then be explored in detail with regard to how concern is defined and measured. Literature will be reviewed on parents’ experiences of expressing concern and health care professionals (HCP) practices of eliciting and attending to parental concern. Select conceptual perspectives on parental concern will then be presented. These were identified mainly during the analysis phase as potentially useful to assist in interpreting the findings. According to Wu and Volker (2009) qualitative researchers should use theory creatively to enhance a study and articulate why they are being used. In terms of the current study they will be used to both make sense of the findings as suggested by Wu and Volker (2009) and to interrogate the theoretical literature within the context of IPA (Smith et al. 2009). The chapter will conclude by summarising empirical and conceptual knowledge in relation to parental experiences of parental concern and provide a rationale for the study.

Search strategy

Searches were conducted on electronic databases; Academic Search Complete; CINAHL with full text; MEDLINE; Psych Info; and SocINDEX. Keywords used for searching included parent* concern OR parent*perception OR parent* experience AND child development OR growth. Limiting the results to peer-reviewed papers yielded an output of 149 dated from 1967 to 2013. Hand searches were carried out on the reference lists of these outputs which further identified potentially relevant
studies. All electronic and manual search outputs were screened and research papers were included based on the following criteria: published in peer-reviewed journals; parents’ or HCP perspectives on parental concerns/ experiences/ perceptions; reference to preschool children; focused on health rather than abuse or illness; and published in the English language. This resulted in 68 studies on parental concern included for review in this chapter.

In terms of the conceptual literature the search strategy was narrower in focus as the purpose was to search for information about the relevant concepts simply to introduce them and describe what they are. Consequently a search of Academic Search Complete and CINAHL with full text was undertaken using the Boolean phrases: ‘parental uncertainty’; ‘lay knowledge’ and ‘help-seeking behaviour’. The rationale for using these phrases will be discussed later in this chapter.

**Empirical perspectives of parental concern**

The aim of this section of the chapter is to review the empirical literature on parental concerns. Firstly previous research is reviewed on what parents are concerned about and when these concerns occur. Then the literature will be reviewed to assess how parents formulate a concern and how they seek help. Parents’ experiences of seeking help and HCPs practices in eliciting and attending to parental concern are then reviewed.

**Source of parents’ concerns**

It is widely acknowledged that even when children are growing and developing normally, parents still worry about them. A number of researchers have found high prevalence rates of parental concern. Percentage rates of parents with concerns such
as 45% (Glascoe 2002), and 45.5% (Restall and Borton 2010) were found, but others found less, such as 30% (Ferguson 2005) and 39% (Coghlan et al. 2003). These figures indicate that many parents are concerned about their children. Kent (2000) an American general paediatrician, in an online blog targeting HCPs, stated that parents bring their child to the paediatrician’s office because they ‘just want to make sure’ all is well and suggested that the code ‘worried well’ should be used for billing purposes. Contrary to the seemingly naïve and possibly dismissive assumptions of Kent, Reijneveld et al. (2008) found 49.3% of all parents in a Dutch representative sample (n=4107) reported some concerns with their child and 8.7% reported frequent concerns about their 14 month to 12 year old children.

Reijneveld et al. (2008) used this national survey to assess the prevalence of parents’ concerns about their children’s development, identify at-risk groups and assess concordance between parental concern and HCP concern. As well as the Child Behaviour Checklist, parents completed a structured questionnaire answering either: ‘no’, ‘frequent’ or ‘some’ to questions regarding concerns about their children in the previous year in relation to specific domains. Behavioural problems were reported by 26% of parents and developmental delay by 13%. However no more specific detail was provided about the developmental delay category in this study. The parents (21.8%) who had frequent concerns and had not sought professional assistance were asked in an open question to identify why they had not sought assistance. The top three reasons were: lack of knowledge of appropriate healthcare provider; confidence that the problem would resolve; and difficulties accessing help. The problem of accessibility was surprising because the Netherlands has a dedicated, freely accessible preventative child health system. However those who had not sought help
were from very marginalised segments of the population including, unemployed, immigrants, on low income, one parent family, young parent or parents with low education level. The lack of knowledge in relation to what to do about child development concerns raises questions about how parents access HCPs to express their concerns and how do HCPs facilitate parents to express these concerns. Addressing these questions would provide useful data for policy makers in designing services that proactively seek to address inequalities in access.

Data were also collected from HCPs in the study (Reijneveld et al. 2008) concerning background characteristics and asking HCPs if they considered that the parents had problems with any aspect of parenting. Even though agreement was lacking generally between parents and HCPs on the cause for concern across all categories, at least it was high (87%) for child development concerns. This finding suggests that parents for the most part and HCPs agree in their assessment of developmental concern in children.

Using different methods, Chung et al. (2011) set out to examine the relationship between parental concern, functional impairment and final diagnosis of a sample of children (n=273) in Taiwan. Unlike Reijneveld et al.’s (2008) sample, these children were aged under seven years and were referred for initial evaluation of suspected developmental delay. This retrospective survey revealed six categories of parental concern from the children’s medical records. The areas of concern were categorised as cognition, speech/language, motor, behavioural psychosocial, global delay and a non-specific category. The most common parental concerns were related to motor (51.3%), language (46.9%) and global delays (23.5%). Global delay was always
found as a multiple rather than a single concern. Boys were overrepresented (64.5%) and the average age at assessment was 30.8 months. On inferential analysis, parental concern was found to have a positive predictive value for confirmed disorders of language (94%) and motor domains (88%), (such as cerebral palsy or dyspraxia), (kappa values 0.74 and 0.68 respectively). Predictive value was much less for cognitive disorders, global delay or related behaviour difficulties. Chung et al. (2011) suggest that a possible reason for the accuracy of parental concerns relating to motor and language may be the overtly visible nature of these domains. This permits parents the opportunity to compare definite features such as “falls a lot” in the context of motor concerns with other children which is likely then to lead to earlier detection of developmental delay. Although some of the typical responses such as “not saying as many words as other kids” from parents were presented in a table in this study it is unclear how researchers collected data from parents (Chung et al. 2011 p. 414). A survey is mentioned as are medical records and clinical evaluation but the level of detail is insufficient to assess the quality of parent self-reports.

In relation to the ‘non-specific’ category of concern, 22 parents were described as not having a concern and presumably, although not reported, were instead identified by a HCP. Further exploration of this finding would have added greater clarity to divergent parent and HCP assessment of child development concerns. For example, if more children had been referred on the basis of HCP concerns would this have resulted in more divergence of opinion? Nevertheless the findings in relation to types of concern support other studies (De Giacomo and Fombonne 1998, Kozlowski et al. 2011, Shevell et al. 2001) which have identified language delay as a leading developmental problem in preschool children. The finding regarding more parental
concerns about boys is found in many other studies (Baker et al. 2003, Coghlan et al. 2003, Restall and Borton 2010).

By adopting a very broad child health perspective, Garbutt et al. (2012) conducted a large survey in the USA to assess parents’ (n=1119) perceptions of both child health problems in the child population of their own communities and health concerns about their own children. This study found that there was considerable variation between what parents consider important in terms of child health problems in the community, versus what they considered important regarding their own children. This difference is not surprising as the former was measured with a closed four-point categorical scale from an existing list of 30 major health care issues. An open-ended question was used for concerns about their own children asking parents to identify and rank three items of concern by age group. Concerns for their own children varied over time and by child’s age. Specifically, in relation to concerns for their two to five year old children (n=518), parents identified allergies (26%), asthma (19%), acute infectious diseases (13%), child development (including healthy growth and development) (10.2%). Whereas parents rated allergies (69%) as the greatest child health problem in the community, many of the remainder were child safety or disease related issues. Other important child development problems perceived in the community included ADHD (65%) and autism (38%). No comment was offered as to why these two conditions featured highly although the researchers acknowledged that asthma and allergy problems may have been accounted for by their high prevalence in St. Louis, the study site. It could be that ADHD and autism provoked some fear in parents because of the complexity of these conditions. The child development percentage of 10.2 % is similar to the Dutch figures of 13% (Reijneveld
et al. 2008) adding support to the findings. Garbutt et al. (2012) concluded that "variations in parents’ concerns support the need for physicians to ask open questions about their specific concerns during each visit" (p.6). The sample was large, representative and with an excellent response rate. However, the researchers did not comment on whether differences found between a parent’s community and their own child concerns could be attributed to different question design.

A study examining parental concerns in relation to acutely ill pre-school children (Kai 1996) while not directly relevant to child development nevertheless identified some interesting and potentially useful findings. In this regard it may add insight into Garbutt et al.’s (2012) study as previously reviewed, in relation to what parents believe is a personal threat versus disorders ‘out there’ is the community. In this descriptive qualitative study, data were collected from 95 parents by interview and focus groups. Kai (1996) found that the two key motivators for expression of parental concerns were perceived threat and personal control. The main concerns related to coughs, fever and the threat of meningitis. Aside from the focus on acute illnesses, the perceived threat and personal control could apply to developmental delay. For example, a parent may perceive a threat in relation to a speech and language delay which can be controlled personally by providing more stimulation by reading or seeking a referral to a speech and language therapist. Kai’s (1996) analysis of the strategies parents used indicated “that they watched, checked and tried to make sense of their child’s illness” (p.985). These strategies of watching, checking and making sense are not too dissimilar from the assessing and comparing identified elsewhere (Lucas et al. 2007a, Reifsnider et al. 2000) in relation to child development and growth. The obvious contrast is the immediacy of the perceived
threat with an acute illness. Kai (1996) acknowledged that participants may have been influenced by him as a medical researcher and as a consequence minimised lay concepts in the discussions. He believed that their descriptions of their child’s problems may have been modified in deference to his medical knowledge and they may have downplayed their rich descriptions.

Porter and Ispa (2012) explored childrearing concerns by analysing the postings (n=120) of a sample of parents of children under two year olds to two of the top online parenting magazines in the USA. Using ethnographic content analysis they identified that concerns about child development was the fourth most common parental concern after nutrition, sleep and discipline. The most common concerns within development domains related to motor skills such as not being able to sit, walk or drink independently. Concerns about language were four times more common in boys. A quarter of parents posted concerns wondering if their child’s behaviour or development was ‘normal’ or ‘off track’ indicating a certain subtlety in presenting features. Some parents described comparing their child’s development with other children or child’s older siblings. The researchers suggested that the manner in which HCP advice was quoted, questioned and passed around was a way in which the online community resisted “the traditional diagnostic authority of medical professionals” (Porter and Ispa 2012 p.565). An acknowledged limitation of the study was the lack of knowledge about the representativeness of the parents. However, the study did provide insight into parents’ concerns expressed in an original way. As these were parents sharing their concerns with other parents they possibly felt comfortable describing their concerns in a lay manner and not modified as suggested by Kai (1996) above. The findings support parental preoccupation with
motor and language domains of development as previously found (Chung et al. 2011, Reijneveld et al. 2008).

In summary, findings in this section indicated that parents’ concern about their children is highly prevalent and they worry generally about complex conditions such as ADHD and autism. Parents watch, check and talk with other parents about their child’s health and development. They are good at identifying overtly visible development delays such as motor and language delays.

**Timing of the onset of parental concern**

Timing of the onset of parental concern is of interest because it is from that point to expressing the concern to a HCP, and from verbal expression to the child being seen at second tier or specialist services, where potential time delays occur. In a sample of children (n=82) referred consecutively with PDD or ASD in the UK the age of onset of parental concern was found to be 30% by the first birthday and 80% by the second birthday (De Giacomo and Fombonne 1998). An onset of developmental delay prior to 36 months is a mandatory criterion for the diagnosis of autism and other PDDs and the findings indicated that parents were identifying the delay early. The first parental concerns were related to speech and language, a general developmental delay as opposed to any unusual PDD symptom. Health visitors and GPs were the first HCPs consulted reflecting typical UK service organisation. Social class and place of residence did not impact on the interval between first parental concern and professional advice sought. Although boys far outnumbered girls, the mean age of first concern was lower for girls (De Giacomo and Fombonne 1998). Most children had an older sibling which was associated with earlier recognition of delay in terms of age possibly because parents had more knowledge of normal development.
Taking a broader developmental delay perspective, the source of delay, age of onset of parental concern and timing of specialist assessment were studied by Shevell et al. (2001) in Canada. They conducted a prospective survey of all children under five years (n=258) in a specific time period who were referred for specialist evaluation for suspected developmental delay. They found that the two main diagnoses for the children studied were global developmental delay (35.7%) and developmental language disorder (32.1%) with others such as PDD, PDD-NOS and isolated motor delay such as cerebral palsy accounting for the remainder. Only 7.8% of the referred children did not have a delay confirmed, indicating that the initial primary care physician’s assessment of the clinical need for referral was warranted. The mean age of initial parent concern was 22.9 months and speciality assessment took place at a mean of 15.5 months later illustrating a sizeable delay. However, expressing parental concern or ‘self’ as a source of referral as described in the study, occurred in only eight cases. This finding is unsurprising as the focus of the study was on tertiary assessment rather than the primary HCP as the first point of contact. The researchers suggest that delay between initial concern and specialist assessment may be to do with a ‘wait and see’ approach rather than waiting lists or a delay in parents initially expressing concern. Notably, there was nearly full parental compliance with investigations which Shevell et al. (2001) noted to be indicative of the need for parents to know the origin of their children’s developmental delay. This study (Shevell et al. 2001) is frequently cited in terms of the time delay from parents initial concern to specialist referral. However, the researchers caution that the findings are not generalizable outside Montreal. This point is important because most of the findings in relation to time delays were determined by local referral arrangements.
Another study was conducted in Canada by a research team of Physiotherapists (PT) and Occupational Therapists (OT) (Ehrmann Feldman et al. 2005) to identify the onset of concern and who first noticed gross motor and/or fine motor neurodevelopmental problems. From an original mixed methods study of 224 parents a sample of parents (n=92) of pre-school children aged from birth to six years awaiting rehabilitation was selected for face to face interviews. The interview schedule was relatively structured and included a number of instruments to measure the child’s functional status and family empowerment. From parent reports the average age of first concern about a gross motor or fine motor problem was one year and average age at referral to rehabilitation was 2.6 years. According to Ehrmann Feldman et al. (2005) the time lag between initial concern and referral to rehabilitation was greater where the parent expressed the concern which suggested that professionals may not accept or validate the lay perspective of parents. Poon et al. (2010) described this as medical practitioners adopting a ‘wait and see’ approach. Ultimately this strategy further delays referral for in-depth diagnostic assessment with possible adverse impacts on the child and family. Organisational difficulties such as long waiting lists were cited by Ehrmann Feldman et al. (2005) as reasons for the time delay. This finding serves to make it all the more critical for concerns to be detected as early as possible and seems contrary to developing high quality responsive services.

The perspectives of fathers in relation to child development problems are rarely examined in the literature. Baker et al. (2003) set out to assess both parents assessment of child behaviour problems using the Child Behaviour Checklist in a sample of developmentally delayed (n= 82) and non-delayed (n=123) pre-school children at 36 and 48 months in the USA. Their results indicated significant
agreement between mothers and fathers on this measure. However, the researchers acknowledged that because these children were attending early intervention there may already be more father involvement and parental discussion about care. This may account for the level of agreement on care after diagnosis. This study did not address agreement between parents prior to referral and diagnosis and suggested that the initial concern originated with mothers.

Also examining both parents, Cepanec et al. (2012) found that mothers and fathers (n=422) from Croatia differed in the Communication and Symbolic Behaviour Scales Developmental Profile (CSBS-DP) Infant-Toddler Checklist which measured parental concern. The average concordance was 78% with fathers scoring lower, sometimes placing the child in a different category, with the trend more pronounced for girls. Cepanec et al. (2012) concluded that it was not a reliable tool to measure parental concern. No information was provided in relation to cultural and parenting norms in Croatia, such as fathers’ involvement in child care, which could have added to an explanation of gender differences in relation to this measure.

Ehrmann Feldman et al. (2005), introduced earlier, found neuro-motor problems were recognised in equal proportions by parents and physicians but physicians identified the initial concern significantly (p<0.05) earlier than parents. Severity of the problem, education or socio-economic status did not make a difference to who first expressed the concern but in French speaking parents the problem was initially detected by the physician (Ehrmann Feldman et al. 2005), suggesting reticence due to communication difficulties. Continuity of physician was considered to possibly assist early recognition of problems (Ehrmann Feldman et al. 2005) but there was no
evidence that this was probed during the interview. The early age of initial concern and that girls were detected earlier differed from other findings (Shevell et al. 2001) although it was acknowledged that the latter referred to any type of developmental delay. Motor delay is known to be one of the earliest concerns to be expressed to HCPs (Petersen et al. 1998). In a criticism of Erhmann Feldman et al.’s (2005) measurement methods, Glascoe (2006) commented that noticing potential problems and expressing a concern were not one and the same. In other words a parent may notice a potential problem regarding the child’s development but may not necessarily express the concern to a HCP at the point of first noticing the problem.

The findings in this section indicate that parents typically notice developmental concerns regarding their children when they are aged between one and two years old. However there are variations depending on gender and developmental domain, with motor delays being noticed earlier and neuro-developmental problems later. HCPs sometimes noticed developmental concerns earlier than parents resulting in earlier referrals for specialist opinion. There were delays in parents expressing concerns to HCPs and delays in onward referral to specialist. In relation to the latter these were mostly accounted for by specific local organisational reasons.

**Parents perceptions about child growth and development**

Child growth is assessed consistently as a marker of general health and optimum development and it is widely acknowledged that parents attach great importance to it (Wright and Weaver 2007). Monitoring growth, more so than development, actually brings parents in regular contact with HCPs. A survey of child health foundation members found 46% of parents consulted HCPs with concerns about growth (Jellinek and Hall 1994).
Lucas et al. (2007b) conducted a systematic review, combining quantitative and qualitative studies to identify lay and professional views of child growth. They systematically selected 127 lay (quantitative and qualitative), and scientific (predominantly epidemiological) studies and found that ‘parents assessed the size and growth of their infant in relation to “personal constructs of normality”’ (p. 637). From this perspective where a baby appeared healthy and was eating well, growth was less of a concern for parents. Whereas the scientific focus was on the “diagnostic value of ‘abnormal’ results” and providing reassurance to parents about ‘normal’ results (Lucas et al. 2007b p. 639). The researchers found some evidence to suggest that where growth rate was low, parents associated this with an underlying problem. While there were some mutual similarities between lay and scientific views, the review ultimately identified differences between lay and scientific views on infant size and growth with the former focusing on making sense of infant growth cognisant of the child’s family and health status. This review revealed potential challenges for parents and HCPs communicating about child growth concerns in a clinical setting.

In a follow-up publication, Lucas et al. (2007a) provided more detail on the 19 studies of lay views included in the systematic review above. The studies reviewed represented 3590 individuals, mainly mothers (n=1948) but also HCPs from the US, Canada, Finland and the UK. The age of children was frequently not stated but where it was, studies referred to infants in the early postnatal period and children up the age of five years. The review found that in their search for norms, parents compared size and growth against reference points such as other infants and children both inside and outside the family, clothing size and growth charts in the clinic. Parents sought explanations for size differences in family history, medical reasons, quality of care
and fatalism. When parents were unable to find explanations, then their child’s growth or size became a worry. Even though parents had low levels of concern as described by Lucas et al. (2007a) about size they placed a high value on growth monitoring citing it as the most common reason for clinic attendance.

Other influences on parents’ opinions include family, friends, media and health professionals but little detail was provided. The quality of the studies included was judged by Lucas et al. (2007a) to be low, particularly among the qualitative studies, on the basis of insufficient methods reported. From the evidence presented in this review it can be concluded that there are gaps remaining in knowledge about how parents formulate concerns about their child’s growth. For example, the influence of partners and families were not explored and inclusion of the ages of the children would have added further clarity to understanding changes in parents’ views over time.

In view of the importance of child growth to child health and well-being a study by Jain et al. (2001) is worthy of highlighting in terms of detail on methods and findings. Jain’s (2001) qualitative descriptive study was carried out in Ohio with a sample of 18 low income mothers enrolled in a Women, Infant and Children (WIC) clinic. Children were aged two to five years old and at-risk for obesity on the basis of data from WIC records. Data were collected from parents using three focus groups and findings indicated that mothers perceived children to have a weight problem if it affected their activity levels or health. Children becoming inactive or being teased by peers were acknowledged by mothers to cause concerns. Mothers did not define overweight or obesity according to standard growth charts, of which there was
distrust. One mother wondered “when is there ever an average child …everyone is different” (Jain et al. 2001 p. 1141). There was a lack of definitional congruence in terms of concern about overweight and obesity between parents and HCPs which supports Lucas et al.’s (2007a) analysis of the lay and scientific divide. In Jain’s (Jain et al. 2001) mainly African-American sample being ‘big boned’ or ‘large framed’ was considered culturally acceptable. Although most of the children were overweight the mothers who themselves were overweight or obese, were unconcerned about them. In this context the HCPs are more likely to be the ones expressing concern about overweight and obesity.

Child growth is often equated with health and a number of descriptive qualitative studies published since Lucas et al.’s (2007a, 2007b) reviews have explored this phenomenon. Three of these related to parents views of growth, health and weight (Garrett-Wright 2010, Redsell et al. 2010, Small et al. 2009), with children who were either of normal weight or overweight. Small et al. (2009) conducted an exploratory study in the USA with 11 immigrant Mexican and Mexican-American parents of preschool children. Contrary to Jain et al. (2001) these parents equated excess weight with being unhealthy and that obesity is caused by the way children are raised. However they admitted uncertainty about knowing or not knowing if their children were overweight. Small et al. (2009) suggested that the differing views from this sample may be an effect of acculturation. Acculturation refers to the fact that these Mexican parents had been living in the US for a number of years and their views differed from their own parents. They had noticed an increase in their own weight within weeks of arriving in what they perceived was ‘the land of plenty’, the USA.
While this made them think about what was happening with their children’s weight uncertainty about what was normal prevailed.

Garrett-Wright (2010) used descriptive phenomenology to examine the factors that determine for parents (n=115) the development of a weight problem in pre-school children in Kentucky. Data were collected by interview and analysed by content analysis. Similar to Small et al. (2009) parents expressed uncertainty about knowing appropriate body weight in children aged two to five years. Parents relied on subjective observations and feelings about energy and activity levels, mood, feelings of intuition such as ‘I can tell’, comparisons with other children and ‘just by looking’ at the child. Parents also used more objective sources such as regular check-ups with trusted HCPs, books and internet, clothing size and physical distress in the child such as becoming breathless on exertion. However this latter point was described in the context of other children that these parents had observed. In terms of trusting objective HCPs, parents made comments such as “you go by what the doctor says, because he is the doctor” (Garrett-Wright 2010 p.4). This seems to indicate deference to superior knowledge which differs with the parents in Jain et al.’s (2001) study. No data were provided about the child’s weight status and parents may have expressed different views if they were overweight. Parents in this study were mainly Caucasian and a mix of low and middle income and perhaps not as marginalised as in Jain et al.’s (2001). However the lack of congruence between the large sample and descriptive phenomenology could mean that findings need to be treated with caution.

In the UK, Redsell et al. (2010) examined parenting beliefs about weight. They used focus groups with 38 parents of children aged from one to 11 months. Like other
studies (Baughcum et al. 1998, Laraway et al. 2010) they found that parents believed heavier babies were healthier, and that their size reflected the quality and competence of the parenting. Parents wanted to ‘do their best’ and were found to be heavily influenced by family and friends in introducing early weaning, despite it being a risk factor for obesity. Additionally, repeated weighing by HCPs was found to be a factor in parents ceasing breastfeeding (an obesity protective factor), where there was slow infant growth assessed using now outdated growth charts. Some parents described themselves as ‘panicked’ by objective measures considered to be superior and highlighted the need for HCPs to be more sensitive. There was a preference for HCPs who were known and respected. More than half the sample of parents was overweight or obese themselves but data on infants’ weights were not provided. Parents did not consider their own children at risk of overweight or obesity and like other studies (Gueron-Sela et al. 2011, Thomlinson 2002) were more concerned about their children being underweight than overweight. Consequently they were unlikely to take action and express a concern.

Moore et al. (2012) studied a stratified random sample of 1,500 parents of children from pre-school to 9th grade. The aim of the survey was to identify the factors that influence parental concern about obesity and its management. Unlike the studies above they found that significant predictors of parental concern were if the child was female, and overweight or obese by BMI status and parent perceptions. Analysis revealed that those who were ‘concerned’ as opposed to ‘unconcerned’ were significantly more (p=0.042) likely to intervene to manage their children’s health problems (Moore et al. 2012). Therefore parents need to perceive that there is a problem with their child’s weight in order to be concerned and then to act. This
finding was supported by Morse (2010), albeit more so with boys. Similarly, Rosado et al. (2013) found that intention to take action occurred when parental concern was associated with obesity rather than overweight in children of migrant Latino farmworkers (n=495) suggesting that concern increases with weight problem severity.

Children being perceived as underweight, even on the ‘bottom’ or lower quartile of the centile chart, was viewed negatively and a cause for parental concern (Laraway et al. 2010, Sullivan et al. 2011) and even worry and guilt (Gueron-Sela et al. 2011). Worry about underweight and feeding difficulties was found by Gueron-Sela et al. (2011), to contribute to some mothers attempting interfering and other relatively unstructured feeding interventions with their children. This is akin to Wright and Weaver’s (2007) description of the ‘worried well’ case where parents become so anxious about their child’s eating that HCPs are triggered to intervene inappropriately. Another group are the ‘unworried falterers’ who are parents who don’t share HCP concerns about growth (Wright and Weaver 2007). It is necessary therefore for HCPs to shift the focus from weight surveillance to working with parents to develop constructive feeding intercessions (Gueron-Sela et al. 2011, Wright and Weaver 2007).

Thomlinson (2002) used descriptive phenomenology to generate rich description about the lived experiences of families of children who had Failing To Thrive (FTT) in the USA. From interviewing 21 mothers, fathers, and grandmothers she identified

---

8 “Failure to thrive (FTT) is a term used to describe inadequate growth or the inability to maintain growth, usually in early childhood. It is a sign of under nutrition, and because many biologic, psychosocial, and environmental processes can lead to under nutrition, FTT should never be a diagnosis unto itself” (Cole and Lanham 2011 p.829)
that they described living with ‘all-encompassing fear’ about the faltering growth (Thomlinson 2002 p.537). In particular, participants spoke about the comparisons they and others made with other children. They were upset or felt blamed when others asked if the child had started eating yet or if he had grown. Comments such as these were perceived as calling into question their competence as parents. No suggestions were given as why other people were quick to negatively and overtly judge parents in such a direct way. For example were others perceived as intervening to protect children from potentially neglectful parents?

Formulating concerns featured in an ethnographic study of low income mothers (n=22) of growth deficient children by Reifsneider et al.(2000). They found mothers monitored their children’s growth using the methods available to them, comparing clothes sizes, other children and accessing HCPs. Parents were found to reject the biomedical assessment of size as an outcome of growth. Parents spoke eloquently of the illnesses and allergies that they believed caused their children’s growth to falter in an ‘illness versus heredity’ theme. Mothers believed they had no control over heredity factors but they could limit a child’s exposure to allergens and illnesses which could affect growth. This view could also apply to child development. Some mothers who used growth charts to monitor or ‘keep track of’ progress saw the changes as a measure of their success or failure, in ‘helping their children to grow’. The researchers recommended acknowledging and addressing maternal concerns to help their children to grow. This means looking beyond the actual measurement of weight to the mother’s specific concerns about how she was intervening, for example with diet and meal scheduling.
Faltering growth was also the focus of 21 parents in Batchelor’s (2007) study in the UK. These parents had been referred by HVs or GPs, to a project for either child feeding problems, poor weight gain or weight loss. Children were aged between 18 and 36 months. Findings from semi-structured interviews and content analysis revealed that some parents initially worried that they would have been perceived as over-anxious or had feelings of guilt that they had failed to feed their child adequately.

Parent perceptions in this section were about growth, particularly weight, rather than development. Parents were found to regularly access HCPs to monitor their child’s size and growth yet adhered to their own ideas in terms of normal size and weight, mostly rejecting standard growth charts. Underweight or faltering growth provoked concern and was perceived as reflecting on the quality of parenting whereas heavier even overweight children were perceived as healthier. Childhood obesity caused parental concern when it was severe and adversely affected the health of the child.

**Parents’ experiences of seeking help and expressing a concern**

When parents perceive that there is a problem in relation to their child’s growth or development the anticipated response is that they would go and seek help from a HCP and express the concern, an action that could prove challenging. Parents in Batchelor’s (2007) study reported struggling with their child’s feeding problems and had been trying to tell their HCPs about this for some time. Since starting with the feeding project they reported feeling relief at being believed and listened to by the project workers. This study indicates that parents may have difficulty in articulating their concerns about child growth in a way that could be heard by HCPs. Similarly, in terms of seeking help and expressing concern, two themes identified by
Thomlinson (2002) were ‘not being heard’ and ‘feeling helpless’. Parents described telling and re-telling their stories and few HCPs paying attention to the fear and anxiety expressed. They described feeling they were being told they were imagining the problems. Feeling ‘helpless’ captured the frustration at not being heard or listened to. These findings support those of Jellinek and Hall (1994) who found that one in four of a sample of parents under 20 years of age (n=840) reported that their concerns of child growth were not taken seriously. This indicates that little has changed in the intervening years. Reassuringly and in contrast there were also parent descriptions of ‘being nurtured’, where validation and encouragement were forthcoming from HCPs (Thomlinson 2002) which may have eased parents experiences of having concerns about their children.

Non-validation of parents’ perspective was found by Lok et al. (2012) in the Netherlands. They investigated the impact of objective hearing screening or self-reported parental concern, on GP referral and/or treatment for hearing problems. A large sample of parents (n=2684) of children under one year completed a survey. The percentage of parents who presented to the GP with concerns about hearing was 18.6%. Despite this being lower than the 20% Dutch incidence of hearing problems, findings indicated that more referrals were made on the basis of objective screening rather than parental concern. Lok et al. (2012) concluded that it may reflect clinical uncertainty about hearing loss in young children. Nonetheless the results suggest that GPs were not as swayed by parental concern and that scientific knowledge is privileged over lay knowledge. Although there was a good response rate (78%) the sample did contain more parents of higher socio-economic status who tend to have better health (Lok et al. 2012).
In contrast, scientific knowledge was not privileged over lay parental knowledge in Willinger and Eisenwort’s (2005) study. These Austrian researchers aimed to assess the accuracy of parents (n=55) concerning child functioning in language and gross motor development in children aged three to six years. Findings indicated that there was no difference in accuracy in the existence of child development problems between mothers who self-referred to the clinic compared with those who were referred by a HCP. However, parental concern was not always found subsequently to be accurate as they significantly overestimated the level of their children’s vocabulary and gross motor skills. This study indicates that scientific and lay knowledge are both valued and ultimately required in the accurate assessment of child language and gross motor development.

Bailey et al. (2004) conducted a longitudinal survey of a representative sample of parents (n=3338) across 20 states in the USA. These families were already enrolled in an early intervention programme for children diagnosed with or at risk of a developmental disability. Using telephone interviews they found that those with children with developmental delay as identified by parents, experienced more frustration in accessing services than those either with a diagnosed disability or those at-risk of developmental delays. Although not discussed in detail entry to the intervention programme required a demonstrable developmental delay and there may have been reluctance on the part of HCPs to confirm this in relation to more subtle forms of developmental or behavioural delay. Inequalities in access to services were found in marginal ethnic groups, those from low income families and where parents had low educational levels. Reasons for this were not given but Bailey et al. (2004) found that poor, black, low income families reported wanting more involvement in
decision-making with HCPs. This suggests that white parents of higher socio-economic status had a more participative role in discussing interventions for their concerns with medical professionals. The study was representative across socio-economic groups and recommendations to address inequalities in accessing help were suggested.

Worry was found by Ellingson et al. (2004) to be a strong predictor of parental help-seeking in Connecticut. Their study was a cross-sectional survey of a representative sample of parents (n=269) of 11 to 39 month old children with developmental and behavioural problems. Worry was rated on a five point scale in three questions on social, behavioural and emotional health. Along with parental worry, three other factors which were: low social competence in the child; raised parental anxiety/depression and disruption of family routines, were significantly associated (p<0.05) with speaking with a HCP about the child’s behaviour. Ellingson et al. (2004) also found that only 18% of parents who reported behavioural problems on the questionnaire had spoken to a HCP about their child health worries and concluded that HCPs needed to enquire systematically about parental concerns, a recommendation supported by Sheldrick et al. (2012). Ellingson et al.’s (2004) figure of 82.3% of worried parents not expressing concern to a HCP is far greater than that found by other researchers (Glascoe 2002, Restall and Borton 2010) and just reinforces the need to find out what will help them to do so. A possible reason for the very high percentage may relate to the behavioural nature of some of the problems and the difficulty in distinguishing normal and atypical behaviours. This may also apply to communication disorders.
In terms of communication disorders, Skeat et al. (2010) in a longitudinal quantitative study examined whether parental concerns about speech/language and behaviour/socialisation as measured with Parental Evaluation of Developmental Status (PEDS), predicted parental help-seeking. Communication was measured with the Communication and Symbolic Behaviour scale (CSBS). A sequentially recruited large sample of parents (n=1911) of pre-school children in Australia were surveyed at four time periods. These children had communication disorders and were participating in a community based language intervention programme. Help seeking was measured as a positive response in relation to the question ‘have you sought help in the past 12 months?’

Results indicated that overall 54.9% of parents sought help and 20% of parents sought help for communication concerns in children at least once, mainly between the ages of three and four years. The strong predictors of help seeking were parental concern in relation to speech and language (p<0.001), female gender of the child (p<0.01) and communication difficulties such as speech intelligibility rather than delay, as measured with the CSBS (p<0.001). However, many parents who had concerns did not seek help and the researchers suggested that this may be because of rapid changes in communication skills which parents may be happy to let develop over time. It could be argued also that parents may lack the knowledge to discern what is and is not delay in terms of language skills. In addition there were parents who had no concerns as measured with the PEDs and yet sought help indicating lack of specificity in the instrument. Between the ages of two and three years children tend to be understood by their families but not by strangers, whereas there should be
marked improvement in intelligibility between the ages of three and four which may account for more help-seeking by parents at this age period.

Addressing parental concerns before school entry is widely acknowledged to be an important goal. Restall and Borton (2010), in addition to identifying prevalence of parent reported developmental risk for school entry children, carried out a mixed methods study in Canada to explore the experiences of parents about identifying and accessing services to manage developmental disabilities. The initial sample of parents (n=290) were surveyed using PEDS and then a purposeful sub sample (n=9) were interviewed. Parents wanted to do the ‘best they could’ for their children and four themes were identified: personal resources; other demands and stresses; information to meet needs; and organisation and delivery of health and social services.

The first two themes were found to be within the parent’s personal and social environment and included financial and social supports, personal persistence and confidence, parenting demands and family stresses. The remaining themes referred to the environment where help was sought. The themes: accessibility to information and publicly funded services; and relationships with trusting and respected HCPs; permitted ‘system navigation’. Relationships with HCPs in particular were found to be vital for parents to be able to express their concerns which support previous studies (Watson et al. 2006, Williams 2007). Although the relationship findings were also supported, the quality of the study was marred by the complete absence of any parent narrative. This could have provided insight into the influence of the parent’s personal and social environment in their quest to access services.
The search for a diagnosis of dyspraxia\(^9\) was reported to be very challenging by most parents (n=11) in Ahern’s (2000) descriptive phenomenological study about children with movement difficulties. Results indicated that parents spent between six and 30 months trying to achieve a diagnosis for their children and they had consulted between one and six professionals including GPs, paediatricians, teachers, and a child health nurse, during this time. The average age of first concern was four years and mothers were more concerned than their husbands (Ahern 2000). In fact one father denied there was a problem with his son and was explored as a negative case. He believed his son was gifted intellectually. When parents described their children’s behaviours they described how cautious and frightened they were of doing things like riding a tricycle or playing with a ball. The problems were subtle, such as problems eating with a knife and fork at the age of six years, but they affected activities of daily living. This subtleness of the delay features may account for the finding of the main theme which was labelled “something is wrong with my child”. Most parents reported that their children had about 25% of their milestones delayed illustrating that assessing milestones can be a crude measure. However it was the accumulation of their children avoiding doing things and the effect on them psychologically that prompted parents to try and seek help for them.

Parents experiences with professionals were mainly negative to the extent that the theme was labelled ‘fighting professionals’. Interestingly eight parents were described to have approached professionals in one of two ways, the first was to ask a “vague non-specific question” about the concern (Ahern 2000 p.195). This approach

\(^9\) Dyspraxia is a disorder of gross and fine motor development characterised by clumsiness, lack of coordination and sometimes language problems. May be visible from an early age but often not diagnosed until entry to school. (NHS Choices 2013)
was found to be dismissed and the concern invalidated by the professional. It made parents doubt themselves. The second tactic was to make a specific request which led to action. This approach usually occurred when the parent had almost identified the problem themselves. Arriving at a correct diagnosis alleviated parental anger and defensiveness. Ahern (2000) suggested that it was the anger which provided the trigger to keep seeking help when it was not forthcoming. These findings capture a high degree of uncertainty in parents as they tried to make sense of what was happening with their children. It took them a long time to identify that there was a developmental problem and nearly equally as long trying to convince HCPs using their intimate lay knowledge of the child. It seemed to be the psychological impact on the child which prompted seeking help.

An eventual diagnosis was similarly hindered until after starting school in Williams’s (2007) study. She interviewed eight mothers whose children had subtle developmental delay and findings indicated, that in line with previous research mothers became concerned about their children in the pre-school period when their experiences of their children did not match “their own beliefs of how their children should be” (Williams 2007 p.285). This illustrates that parental concerns were often subjective and not reliant on objective measures of development such as milestones as mentioned above. Williams (2007) found that part of the problem of parents getting their concerns validated related to the belief that scientific ‘truths’ were held to be more valid than mother’s knowledge and that communication with medical practitioners was poor. It was suggested that the HCPs adopted the position that if the child looked ‘OK’ then they were ‘OK’ and parents were told the child was ‘fine’ after a ten minute consultation. Ultimately parents were not seen as experts with their
own children. To recall from the thesis introduction, working with parents and valuing their expertise in relation to their child is contained within guidelines for HCPs (Department of Health 2009, Health Service Executive 2005a) and yet the contrary is evident in practice. Some mothers withdrew into the support of family rather than come forward and express their concern to a HCP. Consequently, the children’s problems (only one was documented which was Aspergers) were not picked up until they came to the attention of educational and health professionals in the school setting. Findings also included guilt for failing to be ‘good mothers’ for those whose child did not have a smooth developmental path.

Very little information was provided about the nature of parent and professional interactions in this study but from some clues they seem to be brief ‘ten minute’ office based consultations with ‘medical professionals.’ Only two short participant narratives are provided. One was a narrative relating to a GP’s unusual comment of personalised dismissal to a mother and did not resonate with other studies. Therefore the included narratives did not enhance the credibility of the study. However findings did indicate that the existence of a therapeutic relationship and time are important to support parents expressing their concerns. Additionally, eliciting the specific knowledge of mothers in relation to their children is vital to understanding deviations from normal development.

Lay knowledge and relationships with HCPs were also features of Ryan and Salisbury’s (2012) qualitative study. The purpose of this study was to identify possible improvements in the management of primary care consultations with parents of children who may have autism. A maximum variation sample of twenty four
parents pre-diagnosis experiences of Autistic Spectrum Conditions were explored. These parents from across the UK were recruited through snowballing and online support groups. From lengthy interviews and thematic analysis Ryan and Salisbury (2012) categorised parental concern into no concern, passive concern and active concern. No detail was provided on how many parents were in each category. In the category of ‘no concern’ the concern was raised by either a HV or school teacher, and diagnosis was delayed. One parent in this category described her child as different but thought he was ‘gifted’, which was also found by Ahern (2000). It was unclear if either of these two children was a first born child but if they were it would not be surprising if inexperienced parents focussed on the cognitive domain where their child may have been excelling, as perceived by parents and thus overlook, or not even see, deficits in the social and emotion domains of development.

In Ryan and Salisbury’s (2012) study, passive concern described those parents who had a concern about development but had not expressed it to a HCP (GP or HV). A parent in this group described being unable to articulate the concern as a reason for not going for help. One parent said that she was not going to go to her GP and say “I have got a naughty boy” (Ryan and Salisbury 2012 p.3). It is clear that parents struggled to find words and phrases to describe what was happening with their children which may have made them reluctant to talk about it to a HCP, out of fear of embarrassment.

Active concern was where concerns had been raised. Some parents in this group realised very early ‘they could just tell’ or they ‘just knew’ but then experienced difficulties trying to convince, mainly their GP, and sometimes their HV, to accept
their concerns. Many parents did not feel that their concerns were validated and described feeling ‘let down’ and isolated. As a result of the brevity of the publication Ryan and Salisbury (2012) indicated that they posted further methods and findings from this study on the website www.healthtalkonline.org. This online publication (Health Experiences Research Group 2013) has scant method details, making it very difficult to assess rigour. Nevertheless, data extracts provided from the study interviews clearly resonate with parents visiting the website as they posted affirmative comments. Study interviews were reported to take one to three hours. Analysis about how parents formulated their concerns is not provided in either publication. This is disappointing as the researchers stated that it was the first such study qualitatively exploring the experiences of parents of autistic children. Nevertheless, implications and appropriate practical recommendations for general medical practice were provided, complying with the aim of the study. These relate to improved professional knowledge of autism and improved listening skills to enhance the doctor-patient relationship.

In summary parents’ experiences of seeking help for a child growth or development concern were found to be challenging. Parents experienced difficulties in appraising growth and subtle forms of delay in their children. They were uncertain and lacked knowledge of normal growth and development. Some parents had concerns and did not express them. Other parents had concerns and described not being validated; feeling helpless; or ‘fighting with’ professionals. Parents were not seen as experts in their own children.

**HCPs’ practices in eliciting and attending to parental concern**

Using a model of developmental surveillance in the delivery of child health services
requires HCPs to elicit and attend to parental concern (Council on Children With Disabilities Bright Futures Steering Committee 2006, Garg and Dworkin 2011, Glascoe 2000b, Glascoe 2002) at all interactions with parents. However, it is clear from the preceding sections that parents do not readily or easily express concern about child growth and development. Additionally parents did not describe many positive experiences of HCPs practices in promoting expression of parental concern.

To recall from an earlier section the concept of parental concern has been researched extensively by paediatricians Glascoe and Dworkin which they defined as parental “judgements about the way children are developing or behaving” (Glascoe and Dworkin 1995 p.830). Glascoe and Dworkin (1995) categorised the information that can be gleaned from parents into two broad categories which were description and appraisal. Description involves recall and report and is a non-judgemental depiction of children’s skills. For example, parents can be asked to recall the timing of developmental milestones such as when the child started to walk. Parents may be asked to report if their child uses certain words. Appraisals are considered by Glascoe and Dworkin (1995) to be opinions or judgements, composed of estimations, predictions and concerns. For example, estimations require parents to give a numerical estimation of child’s developmental age such as “how old does she seem to you” (Glascoe and Dworkin 1995 p.830). Predictions require an opinion about how a child will behave in the future. According to Glascoe (2002) neither of these two appraisals is used much in practice or research. However concern can be elicited by asking parents “please tell me any concerns about the way your child is behaving, learning and developing” (Glascoe and Dworkin 1995 p.831).
Glascoe (2001) stressed that combining standardised parental reports with parental concern was effective in early screening for developmental and behavioural problems. This was considered necessary because taking parental concern on its own would result in significant under and over identification or excessive referrals, a view supported by others (Reijneveld et al. 2008, Skeat et al. 2010). Glascoe (2002) traced the history of parental concern and its usefulness in early detection of developmental delay back to a seminal paper by Hickson et al. (1983). This study aimed to identify the concerns of mothers (n=210) waiting to see paediatricians (n=10) in their private offices in Nashville with a view to developing practice. Data were collected by face to face interviews carried out by each of the paediatricians. Results indicated that 70% of mothers had an average of 6.4 non-physical concerns about their child. Developmental concerns accounted for 13% of maternal concerns. The findings revealed that only 28% of parents planned to express these concerns to the physician. This study prompted further quantitative research between Hickson’s colleagues and Glascoe ultimately resulting in the development of the Parents’ Evaluation of Developmental Status (PEDS) instrument which will be discussed later. The motivating finding cited by Glascoe (2002) from Hickson’s study was that nearly 14% of mothers had a developmental concern which was similar to the prevalence of developmental disorders in the USA at that time. This inspired decades of work on the potential value of parental concern as a predictor of developmental disability and as an aid to child health practice.

In her seminal textbook about collaborating with parents in the context of assessing child growth and development, Glascoe (2002) reviewed 29 studies (at least half of which she was involved in) and concluded that parental concern is an accurate
predictor of developmental disability. A wealth of detailed data was provided from quantitative studies in relation to how parents formulate appraisals, what influences expressing a concern and the most effective wording for HCPs to elicit concern in clinical practice. Glascoe and Dworkin (1995) acknowledged that even though the majority of HCPs ask parents about their concerns, parents are influenced by the very wording of the question affecting the quality and value of responses in clinical practice. For example, they advised against using the word ‘worries’ because it had the potential to inhibit parent’s responses. They suggested that the word ‘worry’ has negative connotations which parents may be “reluctant to endorse” (Glascoe and Dworkin 1995 p. 832). They also advised against using complex language about developmental domains which parents may not understand or be familiar with. Examples of lay language include “have you any concerns about how … uses hands and fingers to do things?” (Glascoe and Dworkin 1995 p. 832).

Glascoe went on to spend over 20 years developing the Parents' Evaluation of Developmental Status (PEDS) and has written prolifically about parental concern. The PEDS is designed for use by HCPs in clinical practice to assess child development while incorporating parental concerns. It is a ten item tool composed of eight closed questions asking parents to rate their concerns as ‘yes’, ‘no’ or ‘a little’ in relation to: how the child talks and makes speech sounds; understands what the parent says; using hands and fingers to do things; uses arms and legs; how the child behaves; gets along with others; learning to do things for themselves; or learning pre-school or school skills. Two open questions are provided asking parents to include their own general opinions and any other concerns (Glascoe 2000b). Glascoe (2000b) stressed that the PEDS is quick and simple to administer and can be completed by
92% of parents as it has an average reading level. She suggested that some first time parents could be ‘tentative’ when concerns were being elicited citing examples such as a parent saying they had been worried but that it (the problem) had since improved or “I’m only a little concerned about …” (Glascoe 2000a p.143). She stated that prefaces such as these were to be ignored and what followed recorded as ‘a concern’ in a consultation. The PEDs is interpreted using a simple algorithm. ‘Path E’ is no concern with a clinical decision to review parental concern at the next therapeutic interaction. ‘Path A’ is where there are two or more significant (as determined by age and stage of development) concerns and specific referrals such as to audiology or speech and language therapy required. Psychometric testing of the PEDs indicated that it was a reliable tool with sensitivity\(^{10}\) and specificity\(^{11}\) of 70-80% (Glascoe 2002).

Other assessment tools exist to measure parental concern in clinical practice such as the Ages and Stages Questionnaire (ASQ) (Squires et al. 1997) and the Parent Concerns Questionnaire (PCQ) (Sheppard et al. 2010). However the PCQ is more commonly used in conjunction with the Common Assessment Framework\(^{12}\) in child welfare with vulnerable families rather than typical health or development settings (Sheppard et al. 2010). The ASQ consists of 19 separate questionnaires for each of the monthly ages between four and 60 months. Each questionnaire consists of three sections, which are: a brief demographic questionnaire; 30 items relating to five domains of child development with responses from ‘yes’, ‘sometimes’ or ‘not yet’; and finally seven open questions eliciting parental concerns. The ASQ takes about 10

---

\(^{10}\) Proportion of children correctly identified as having the screened condition  
\(^{11}\) Proportion of children correctly identified as not having the screened condition  
\(^{12}\) The Common Assessment Framework is a standardised approach used by practitioners in the context of safeguarding children to assess children's additional needs and decide how these should be met. (Department for Education 2013)
to 15 minutes to complete and is designed to be mailed to parents and answered prior to attending for a paediatric consultation (Squires et al. 1997). Other tools to assess child development such as the Infant Development Inventory and the Child Development Inventory (Ireton 1992) may rely on parental reports but do not assess parental concern. In contrast, the basic premise of the PEDS and ASQ tools is that they can be completed by a parent while they are waiting to see their healthcare provider. While the ASQ and the CDI were found to be easy methods to use by parents in the clinic setting, their accuracy did not meet required Battelle Development Inventory (BDI) gold standard (Rydz et al. 2006).

The PEDS was used in Australia by Coghlan et al. (2003) to test its usefulness for reporting developmental concern. This cross-sectional survey had a convenience sample of parents of pre-school children (n=262) attending kindergarten services who were at medium and high risk of developmental problems. The children were aged from 18 months to three years. In addition to completing the PEDS parents were asked to rate their ease of understanding and ease of completion. Results revealed that 9% of children were at high risk and 19% at medium risk of disabilities which was similar or lower to findings in Glascoe’s (2002) USA instrument norming population. However, Coghlan et al. (2003) did not measure the developmental status of the children so the accuracy of the measure cannot be verified with the Australian sample. The results also indicated that 98% of parents found the instrument easy to complete. Most parents (89%) considered it would be helpful to HCPs. The researchers acknowledged that the study was a limited evaluation as there were no ethnic minorities. It was noted that nearly 12% of the initial study population were excluded on the basis that they were illiterate in English. Figures such as these
have implications for the use of screening instruments in clinical practice with a general population of parents, including those whose first language is not English.

Cox et al. (2010) identified a cultural dimension in testing the utility of PEDS with English and Spanish speaking Americans from two different sites. Children were aged six to nine months in site one and aged three to five years in site two. In a review of PEDS forms (n=752) completed in Spanish or English in medical records, they identified that parents used the forms to elaborate on their developmental concerns but often their knowledge and expectations of development were mismatched. More worryingly however was the finding that written comments did not always reflect the intent of the question. For example, in response to whether there was concern about fine motor skills a parent commented on her six month old child constantly having his fingers in his mouth. As a consequence, Cox et al. (2010) cautioned against the PEDS being used as a substitute for patient and HCP communication. According to Kiing et al. (2012) the PEDS relies on there being a common understanding of the word ‘concern’ among parents and results from Singapore among Chinese and Malayan parents suggest that may not be the case. These findings illustrate the difficulties parents may have in understanding child development and also indicate the dangers of an over-reliance on fallible instruments.

Using different comparisons, Sheldrick et al. (2012) compared parents (n=465) self-reports of concern with a formal screening tools. These were parents of children aged three to 65 months attending routine paediatric care in Boston and they were asked three questions i.e. “do you have concerns about your child’s behaviour?
development? learning?” (p.156). Parents then completed two versions of the ASQ. Results revealed overall moderate agreement between parent reports and the formal screens but higher on the behavioural rather than developmental sections. However of those parents who reported no concerns, 18% were found to be at risk for developmental delay by one or both screens (Sheldrick et al. 2012). This indicates a sizeable number who were not correctly identified. Twenty four per cent had at least one concern. Influencing factors on the ‘more concerns’ item were greater child age, male gender, lower family income (Sheldrick et al. 2012). These results support more probing by HCPs on parents who report no concern.

Glascoe (2002) admitted that the evidence suggested that there were still 20-25% of parents who fail to express concerns even when it is confirmed that their children had developmental problems. She suggested that communication difficulties between doctors and parents primarily accounted for this parental failure to express concerns. It is interesting that she described parents who were inaccurately not concerned, expressing ‘relief or regret’ at a debriefing following diagnosis of a developmental disability. This observation was expressed relatively informally, almost as if the comment was anecdotal and had less value in the midst of an analysis of quantitative findings. Glascoe (2002, 2003, 2006) raised this very point a number of times and believed the solution is for HCPs to repeatedly and systematically ask parents if they are concerned. It reinforces the need to understand the experiences of parents who have the concern rather than blindly persisting with trying to make them express a concern.

In support of screening with formal instruments in practice, Glascoe (2000b) stated
that screening to elicit parental concern is easier than assessing child development skills in an uncooperative child during a short consultation. She also stated that if concerns are not systematically and accurately elicited, over 40% of parents will not express them (Glascoe 2002). Glascoe (2006) stated that reticence may be caused by anxiety and fears that they are over-worrying. Therefore it can be argued that children and their parents are best served in terms of child growth and development by having access to HCPs who create an environment conducive to expressing concerns as well as systematically listening to their concerns.

However, huge variations in child development screening and surveillance practices have been found in the USA, and there is some evidence that physicians under-relied on parent reports (Guerrero et al. 2011, Sices et al. 2003). According to Guerrero et al. (2011) less than one half of a large national representative parent sample in the USA had their child development concerns elicited by a HCP in the previous 12 months and significantly less (p<0.01) for Latino and African-American parents. This national survey used telephone interviews to collect data from parents (n=91,642) of children from birth to five years and had a good response rate of 46.7%. Limitations in relation to recall bias were acknowledged but allowing for that the findings illustrates stark inequalities in the provision of optimum child health services.

A systematic review of US studies (Sheldrick et al. 2011) was precipitated by the view that children with developmental-behavioural disorders are under-identified. Eleven studies from an initial 539 articles were included in a quantitative synthesis. Results revealed that sensitivity of paediatric care providers in identifying
developmental-behavioural disorders ranged from 14-54% and specificity 69-100%. This indicates that paediatric care providers may not be very accurate in correctly identifying children with developmental-behavioural disorders. Paediatricians in some of the studies used diagnostic interviews with parents and children and others used developmental screening tools. Limitations were acknowledged in terms of the paucity of studies for review and lack of points for comparison across the included studies. Similar evaluations have not been undertaken elsewhere.

In terms of HCP practice outputs in the UK, it was found that HVs made the initial referral for nearly 90% of children eventually diagnosed with Pervasive Developmental disorders (PDD) whereas health professionals generally, in fewer than 30 per cent of cases detected Specific Developmental Disorders (SDD) before school entry (Chakrabarti and Fombonne, 2005). These findings indicate significant room for improvement among HCPs in detection of SDDs. The barriers in the USA identified by paediatricians in relation to screening for parental concern were found by to be lack of; policy of standardized developmental screening in their offices; office staff; time; and reimbursement (Hickson et al. 1983, Sand et al. 2005). However as previously discussed formal screening alone does not provide to solution to both detecting parental concern and identifying developmental disability. Perhaps refocusing on working with parents holds the key to success. The evidence shows that it is known that parents often have unvoiced concerns about developmental disorders. However HCPs have been too preoccupied with developing, testing and using screening tools to elicit parental concern and have inadequately researched why parents find it difficult to express their child growth and development concerns.
**Conceptual and theoretical perspectives on parental concern**

The selection of theories for review was not predetermined at the outset of the study or during the literature review as can be expected in quantitative research where theory is typically used as a conceptual or theoretical framework for measurement. For this study the review of conceptual and theoretical literature arose during the course of data collection and analysis prompted by a need to understand parental concern. These concepts were parental uncertainty, lay knowledge, and help-seeking behaviour. While many qualitative researchers “may use the idea of sensitising concepts” they rarely explicitly describe how theory or concepts have been applied in a study (Wu and Volker 2009 p.2730). While acknowledging my interest in the concept of uncertainty from the outset, influenced by my clinical experience and knowledge of this literature, in the context of parent narratives it was clear that parents were uncertain. Their accounts indicated that they drew on their own knowledge that is lay knowledge to make sense of their concerns. Because of their concerns and experiences of uncertainty, all parents spoke of eventually seeking help. The theories reviewed therefore were useful to interpreting the data. As suggested by Reeves et al. (2008) theories are useful to the analysis of qualitative data by providing different ‘lenses’ through which to examine complicated problems and social issues.

**Uncertainty in Illness Theory**

Parental uncertainty as a concept is most commonly associated in the literature with The Uncertainty in Illness Theory (UIT). The UIT was developed by Mishel (1988) and originally related to illness in adults before later including work on parental uncertainty. The two major assumptions of Mishel’s (1988) theory are that a)
“uncertainty is a cognitive state, representing the inadequacy of an existing cognitive schema to support the interpretation of illness-related events” and b) “uncertainty is an inherently neutral experience neither desirable nor aversive until it is appraised as such” (Bailey and Stewart 2006 p. 627). The Uncertainty in Illness theory is organised around three major components: antecedents; appraisal; and coping with uncertainty (Mishel and Clayton 2003).

One of the main antecedents of uncertainty is the stimuli frame, which refers to the form, structure and composition of the initial stimulus perceived by the cognitive capacities of the person (Mishel 1988). Mishel (1988) theorised that a decision-maker, such as a patient or parent, experiences uncertainty when they cannot assign a definite value to an illness-related unfamiliar event or symptom pattern because of insufficient cues. Structure providers which are described as the credible authority from HCPs and other social supports, are available to assist in the interpretation of the stimulus event and may increase or decrease uncertainty. Once uncertainty has been appraised, a range of usual behaviour known as adaptation occurs (Mishel 1988). The UIT scale was developed to measure Perceived Uncertainty in Illness and later modified to capture Parental Perceived Uncertainty in Illness in their children (PPUS).

Four quantitative studies (Hoff et al. 2005, Lin et al. 2010, Santacroce 2000, Stewart et al. 2010) used the Parental Perceived Uncertainty in Illness (PPUS) to measure parental uncertainty in relation to childhood diabetes, cancer, HIV and childhood injury respectively. The PPUS was designed to measure parents’ perceptions of ambiguity, complexity, lack of information and unpredictability in relation to their
child’s illness and hospitalisation (Mishel and Clayton 2003). Uncertainty about illness is significantly associated with parental uncertainty (Santacroce 2000). Lin et al. (2010) found that lower perceived social support was significantly associated with higher parental uncertainty. Santacroce (2001) who viewed the PPUS applicable to parental uncertainty during childhood illness, set about modifying the scale (PPUS-Diagnosis) to be more applicable to the diagnosis phase of the child’s illness. Santacroce (2001) stated that because of the subtle or seemingly unimportant illness cues, the symptom pattern might be more difficult to decipher. This point is relevant to subtlety in relation to developmental delay in children. In contrast with the raised temperature or wheezing evident in an acute illness, parents may be challenged by the subtlety of child growth or development problems to decipher if there is something amiss to be concerned about.

In terms of adaptation within uncertainty, various quantitative studies found that parental uncertainty about their child’s illness had a significant impact on coping and family growth (Lin et al. 2010), family distress (Dodgson et al. 2000), and family routines (Stewart et al. 2010). Even though these studies focussed mainly on childhood illnesses, some authors (Lin et al 2010, Stewart et al 2010) acknowledged that child developmental concerns, although not measured, could further affect parental uncertainty. Magnuson and Hergils (2000) studied parents of children who were delayed in receiving a diagnosis for hearing impairment. They described a linear process from parental uncertainty to adaptation very clearly, which was; unawareness, suspicion, confirmation and habilitation. This supports Mishel’s (1988) conceptualisation. Therefore, parental uncertainty in illness could contribute to understanding the factors that precede expressing parental concern about child
growth and development and trigger action to seek help. However, it is unknown if parents’ sense making of a complex developmental delay would follow such an uncomplicated linear process as described above. It is possible that like complex conditions, the process could have an erratic trajectory.

Like Mishel, Penrod (2007) has written extensively about uncertainty. Her initial efforts were mainly theoretical but her later work in relation to use of uncertainty in practice refers mainly to carers and older people. Nevertheless, Penrod’s (2007) work is useful in capturing the highly individualised discomfiting perception of doubt and not knowing brought about by uncertainty. She differs from Mishel (1988) in her assertion that there are pre-cognitive as well as cognitive ways of knowing and that perceived doubts or uncertainty are experienced but not always analysed at these times. The resulting doubt may be echoed in one’s sense of control and confidence. These further insights on uncertainty may have value in understanding what triggers parental action in seeking assistance for their concerns. It is possible that concern about a child’s growth or development may afford parents a chance to reclaim control by going for help. Subsequent encounters between parents and HCPs in a context of help-seeking provide opportunities for parents to express their lay knowledge about concerns.

**Lay Knowledge**

According to Henderson (2010) the concept of lay knowledge has been debated by health sociologists and public health scholars in the last two decades. It has been variously described as subject knowledge held by an unqualified person, usually gained from personal endeavours or experience and in the view of Prior (2003) is fundamentally different from a similar phrase called lay expertise. Lay knowledge is
presented as narrative, representing the subjective view, in contrast to the objective view claimed in professional knowledge (Massé et al. 2001, Popay et al. 2003a, Popay et al. 2003b). Professional or expert knowledge usually involves skills in diagnosis and management of illness (Henderson 2010). Expert knowledge is seen as originating from formal education and training, enhanced by experience. Glascoe (2002) provided much detail on how professionals form judgements about child development and describes this as judgement heuristics. This originates from “providers’ unique experiences with similar children and beliefs and attitudes about specific conditions and treatments” and contains eight elements necessary to form an accurate impression (Glascoe 2002 p.88).

The impetus in the literature to study lay knowledge stems from an imperative to understand, explain and ascribe meaning to events and circumstances in everyday life. It is suggested that “science seeks to answer questions about causality” whereas “lay knowledge seeks to answer questions about ‘meanings’” (Popay 2012 p.5). In terms of child growth and development problems, parents may be seeking answers to questions such as ‘is this normal or not?’

Most work around lay knowledge relates to health inequalities (Popay and Williams 1996, Popay et al. 1998, Putland et al. 2011) and public participation (Martin 2008). In the view of Popay et al. (1998) it was used particularly to study ‘non-compliant behaviours’. It is also gaining currency in mental health (Pilgrim et al. 1997). Studies relating to lay knowledge of parents and children in child health contexts are scant, although one (Whittaker and Taylor 2004) examined consumer involvement on parenting research. Coveney (2004) conducted a qualitative study with two socio-
economically diverse suburbs in Australia, to explore their knowledge of food and health. The results indicated that working class families saw food in terms of fuel for a *machine* body, necessary for growth and function whereas middle class families viewed food in terms of taste and style and necessary to influence an aesthetic view of the body. Jain *et al.*’s (2001) qualitative descriptive study, already reviewed, found low-income mothers of children with weight problems were suspicious of standard growth charts used by professionals because they did not see overweight as a problem so long as children were active and had good appetites. In terms of the impact of valuing expert over lay knowledge, Henderson (2010 p.4) cautions that there may be a failure to recognise early symptoms of disease by the “privileging of clinical diagnosis” (p.4) which was experienced by parents in Ahern’s (2000) study who reported that HCPs considered that their children were ‘fine’ and yet were eventually diagnosed with dyspraxia. In terms of child growth and development effective care can be undermined or ineffective if HCPs fail to hear what parents are describing about their children as expressed in their own words.

Additionally parents’ beliefs and experiences about health and illness are important for HCPs to be aware of. Gunnarson and Hydén (2009) illustrate this very clearly in a study involving parents in the early phase of the illness trajectory of asthma. The problems experienced were initially interpreted and responded to by parents as normal infant difficulties. Parents made efforts to seek medical attention only when their own strategies failed or partially worked. This was evident in another study (Edmunds 2005) where parents were obviously concerned about their school-going children’s weight but delayed until the problem was well established. This decision-making has obvious relevance to the current study in terms of understanding possible
delay in parental help-seeking for developmental problems. Lay knowledge contributes to expert assessment of child development. According to Glascoe (2002) the information that parents have, can be categorised into descriptions and appraisals which in her view have “uses, strengths and limitations” (p.91). In her view lay and expert knowledge are both needed to promote optimum child development and to detect problems when parents seek help.

**Help-Seeking behaviour**

Help seeking behaviour is a form of social behaviour. It has been defined in terms of actively seeking help from another person, either informally from friends and family or formally from professional sources of help (Rickwood *et al.* 2005). Although lacking a unifying theory, help seeking behaviour has been explored as a means of understanding a person’s delay in going to seek professional help in various health related instances. For example it has been used in studies of women seeking help for postnatal depression (McIntosh 1993), cancer symptoms (O’Mahony and Hegarty 2009) and chronic pain management (Cornally and McCarthy 2011a).

In terms of child health, Eiraldi *et al.* (2006) proposed a model of Help Seeking Behaviour to address unmet need for ethnic minority children and adolescents with ADHD in America. From an empirical study their Help Seeking Behaviour Model (HSBM) has four attributes, namely; Problem Recognition, Decision to Seek Help, Service Selection and Service Utilisation. In terms of Problem Recognition some of the elements are: objective assessment of need; perceived need; other triggers such as identification by professionals; and parent and teacher characteristics. They conceptualised the decision to seek help as influenced by demographic characteristic; fears (about stigma); level of knowledge of ADHD; socio-cultural norms and values;
and parental expectations and attitudes. Services Selection contains elements relating to barriers and facilitators such as economic eligibility and perceptions about HCP support and sensitivity. Service Utilisation elements include the numerous categories of services available as well as quality and integrity features about them. Even though Eiraldi et al.’s (2006) model is detailed, it is focused on ADHD and American service provision which may affect its application elsewhere.

Cornally and McCarthy (2011b) were the first authors to publish a concept analysis of help seeking behaviour. As a consequence of a detailed review and analysis of the literature they defined help-seeking behaviour as “a problem focused, planned behaviour, involving interpersonal interaction with a selected health care professional” (p.286). This definition with three defining attributes contained within differs slightly with Eiraldi et al.’s (2006) four attributes: Problem recognition, Decision to seek help, Service selection and Service utilisation. However Eiraldi et al.’s (2006) Decision to Seek Help and Service Selection are contained within the central Planned Behaviour stage as described by Cornally and McCarthy (2011b).

Cornally and McCarthy’s (2011b) analysis is very useful in terms of understanding the concept. Factors which influence help-seeking such as gender, self-efficacy, past experience and failed self-management were also described clearly.

In contrast with Eiraldi et al. (2006), Cornally and McCarthy’s (2011b) work is a recent concept analysis, using Walker and Avant’s method. It is based on a large volume of general literature with potentially wider applicability. In the context of parental concern, the concept analysis focused on the appraisal of the individual’s problem and not a parent’s assessment of a dependant’s problem. The concept analysis cited Sayal et al. (2010) which was a qualitative study examining parental
help-seeking in primary care for mental health concerns in children and adolescents, along with two other studies relevant to parents. However, no discussion of potential implications of parents seeking help for a dependent child was included. It is possible that an individual seeking help for themselves may be quite happy to delay whereas if they were deciding to seek help for their child they may act quickly. The concept analysis (Cornally and McCarthy 2011b) centred on symptoms of illness not childhood developmental delay. In an article sourced in connection with lay knowledge it is considered that going to the doctor implies a deliberate action (Francis and Hester 2004). Consequently the proactive approach of help seeking for a specific illness or condition as discussed here may differ to universal child health services provided by HCPs where the focus is on provision of preventative services to support parents in the context of routine well-child checks.

**Summary and conclusion**

Parental concern is a prevalent phenomenon of a judgmental nature that parents use to assess problems in their child’s growth and development. Parents have more concerns about boys and are more effective at assessing language and motor skills rather than cognitive and behavioural skills (Chung et al. 2011). This may be related to the externalising nature of these skills which facilitates making comparisons. In appraising their concerns about child growth and development parents are influenced by comparing their children with others (Lucas et al. 2007a, Porter and Ispa 2012, Reifsnider et al. 2000). Heavier children are generally perceived to be healthier and being overweight or obese are not perceived as a problem unless health or fitness are affected (Redsell et al. 2010). However children who are underweight do cause concerns for parents and they are perceived as reflecting on the quality of parenting
(Thomlinson 2002). The typical age of onset of parental concern is between the first and second birthday but it varies in terms of different conditions.

Some studies exploring parental experiences with specific conditions such as dyspraxia (Ahern 2000) and ASD (Ryan and Salisbury 2012) have made attempts to get at the issue of how the concern is formulated and expressed but lack detail. Accessibility to services and trusted HCPs are considered important as evidence indicates that parents report having fears, frustration and having to ‘fight’ with HCPs to have their concerns heard (Reijneveld et al. 2008, Williams 2007). Studies also suggest that parents have varying experiences of HCPs assessing and attending to their concerns. HCPs do not consistently or effectively elicit or attend to parental concern (Bailey et al. 2004). Instruments have been designed and developed for use in clinical practice to capture parental concern about child development. There is evidence that objectively assessed parental concern is a good predictor of developmental disabilities but with varying sensitivity and specificity. There seems to be broad agreement for using tools with individualised HCP assessment to elicit concern. Delays persist in relation to parents expressing their concerns and many parents report negative experiences with HCPs. For parents with concerns who did not seek help the reasons were related to marginalisation, inexperienced parents and those with low education level (Reijneveld et al. 2008)

There have already been more calls for research to explore the role of parents in detecting SDPs in their children (Williams and Holmes 2004) and on why parents with frequent concerns do not seek care (Reijneveld et al. 2008). The empirical literature on parental concern lacks a nursing perspective. This is unsurprising as the
majority of the literature comes from the USA where child health services are delivered by paediatricians. Furthermore, child health services are not universal there either which may account for some of the lack of accessibility identified by parents. Empirical studies reviewed relating to parental concern were not underpinned by theory or did not draw on theory which would have added greater understanding to the findings.

Conceptual and theoretical perspectives of lay knowledge, parental uncertainty in illness and help-seeking were examined and all originate with a health/illness problem which needs to be appraised. Another common feature is interaction with HCPs both in terms of appraisal and adaptation to the health problem. However none have sought to conceptualise the experiences of parents in relation to concern about child growth or development. Nonetheless there is resonance from their use in other applications which are potentially useful to interrogate the findings.

In conclusion the empirical and conceptual literature reviewed indicates a lack of understanding regarding the experiences of parents in relation to expressing concerns about growth or development in their pre-school children. Designing a study to address this gap in knowledge will be addressed in the following chapter.
Chapter 3: Methodology and methods

In this chapter the methods used in the research process will be outlined. In particular, justification for the choice and use of Interpretative Phenomenological Analysis (IPA) will be provided. IPA details will be integrated throughout the various phases of the research process, which are: study sample; access and recruitment; data collection; ethical considerations and analytical techniques. Detail on methodological rigour and reflexivity will also be outlined prior to the summary and conclusion.

Aim

The aim of the study was to understand how parents of pre-school children referred to second tier child developmental services make sense of child growth or development concerns.

Definition of terms

For the purposes of this study:

- Child development was “defined as the processes underlying the change in growth and capability in the child” (Empson and Nabuzoka 2004 p. 36). Child growth and development includes all aspects of physical, cognitive, behavioural, emotional or social change.

- Child growth specifically relates to increase in physical size of a child’s weight, length/height and head circumference as assessed objectively using WHO growth centile charts. Suboptimum growth occurs when measurements lie outside the 0.4th or 99.6th centile (Royal College of Paediatrics and Child Health 2013). For the purposes of the current study child growth concerns related to subjective parent concerns about length/height, head circumference
or underweight\textsuperscript{13}. 

- A pre-school child was defined as one less than five years of age.
- A parent was the biological or legal mother or father.
- Second tier services were defined as any service provided by Multi-Disciplinary Team members such as AMO, Speech and Language Therapist (S&LT), Physiotherapist, or Orthoptist to which the PHN referred in response to a child growth or development concern.

**Research design**

Many studies reviewed in the previous chapter used quantitative designs to measure parental concern in relation to child health or illness. Some qualitative studies explored parents’ experiences or concerns about lack of growth (Reifsnider *et al.* 2000), faltering growth (Thomlinson 2002) and child feeding problems (Batchelor 2007). Other studies explored parents experiences of concern about specific developmental disorders such as dyspraxia (Ahern 2000), autistic spectrum conditions (Ryan and Salisbury 2012), and unspecified subtle developmental delay (Williams 2007). Quantitative studies in the developmental paediatric literature on parental concern have mainly concentrated on instrument development, but this has not resolved the problem of parents delayed expression of concern (Glascoe 2002, Guerrero *et al.* 2011, Williams and Holmes 2004). None of the qualitative studies reviewed have used samples of parents of children who had general child growth and development problems. The limited studies that explored specific child developmental conditions were either insufficiently detailed or lacked rigour in other dimensions such as transferability, dependability and confirmability (Ahern 2000, 

\textsuperscript{13} Child overweight and obesity is considered a large separate topic beyond the scope of the current study.
No study specifically sought to understand the experiences of parents of children referred to second tier child developmental services who had expressed a child growth or development concern. Consequently, a qualitative study was considered appropriate to address this knowledge and methodological gap in the research. According to Biggerstaff and Thompson (2008) qualitative paradigms enable comprehension of the “complexity of bio-psycho-social phenomena” (p. 4). Prior to choosing a definite design it was necessary to explore the relevant ontological and epistemological considerations.

**Ontological and epistemological stance**

Ontology is defined as a branch of philosophical study involved with the nature of being or existence. It is concerned with whether there is a ‘real world out there’ independent of our knowledge. According to Vasilachis De Gialdino (2009) ontology is particularly important to the qualitative paradigm which is fundamentally concerned with people. People have an identity composed of essential and existential components with which qualitative researchers are interested in accessing, in the pursuit of knowledge. From an examination of realist ontology I was drawn to the concepts of critical realism and subtle realism. Denzin and Lincoln (2008) described critical realism as a “third stream, between positivism and poststructuralist” which holds that the world is socially constructed and reality exists on many levels (p.17). Whereas, Cohen and Crabtree (2006) suggest that “subtle realists assume that we can only know reality from our own perspective of it” (p.1). Maxwell (2012) in a detailed analysis of realism, used critical realism in a broad sense incorporating subtle realism and suggested that all forms ultimately deny certainty about knowing the world and accept alternative valid perspectives of phenomena. He defined critical realism as a
combination of ontological realism and epistemological constructivism, and rejected vigorously any potential criticism of this seemingly ontological/epistemological collapse. Maxwell (2012) stated that language is used to a substantial extent to express the concepts we structure about our perception of the world as we live in it. In his opinion critical realism also views that these conceptualisations and perspectives, held by ourselves and those we study, are a segment of the world we want to comprehend, and that our understanding of these perceptions “can be more or less correct” (p.9). This conceptualisation of critical realism was relevant to understanding the perspectives of parents living in the world about their experiences of concerns about their children’s growth and development, as expressed through language, in order to understand and make sense of that phenomenon. This led to an examination of lived experience and phenomenology which will be discussed later. It is appropriate firstly however to explore epistemology in more depth.

It is widely acknowledged that it is vital to the rigour of a study for the researcher to articulate an epistemological stance (Hammersley and Atkinson 1995, Koch and Harrington 1998, Maxwell 2012, Sullivan et al. 2012). Epistemology is defined “as the study of knowledge and justified belief” (Stanford Encyclopaedia of Philosophy 2005 p.1). Adopting a qualitative paradigm to answer the research question and address the aim, entailed, in the words of Finlay (2009) a rejection of the “positivist natural science in favour of qualitative human science” (p.14). The current study on parental concerns aims to generate knowledge from the psycho-social worlds of parents. This implies a need to consider at the outset a social constructionist epistemological stance. IPA is influenced by social constructionism. However Smith et al.(2009) were keen to separate IPA from discursive psychology and Foucauldian
discourse analysis which they considered have a stronger commitment to social constructionism because “discursive representations are the unit of analysis” in generating knowledge (p.195). Furthermore, social constructionism does not hold with viewing the world though a psychological lens (Caldwell and Flowers 2009). It is also considered to lean too much towards relativism (Larkin 2013). Whereas, IPA focuses on the contextual, idiographic and hermeneutic implying “an interpretation of the meaning for a particular person in a particular context” (Smith et al. 2009 p.195).

Embodiment, embodied knowing and the work of Merleau-Ponty are important to IPA in the wake of the previously stated shortcomings of social constructionism. Much of IPA research in health psychology is about making sense of individuals’ embodied experiences when their bodies “appear to go wrong” (Smith et al. 2009 p.199). In the context of the current study the concept of embodied cognition as described by Smith et al. (2009) is relevant as I aim to gain insight of parents’ emotions about making sense of their concerns about their child’s growth and development.

The current study is also concerned with generating knowledge relevant to human interactions in natural settings or ‘a particular context’. Knowing how parents make sense of their experiences in their social contexts suggests the value of symbolic interactionism as an epistemological consideration. Symbolic interactionism “conceives of the self as a social rather than psychological entity”(University of Strathclyde 2013 p.1). As such it concerns making sense of other people’s meanings, the individual who is a ‘meaning maker’ and the relationships between people who
are ‘meaningful’ (University of Strathclyde 2013). Symbolic interactionism is considered highly compatible with interpretative descriptive methodologies and their epistemological origins (Oliver 2011). In the opinion of interactionists the interpretations that people have in response to stimuli are constantly under revision “as events unfold and shape their actions” (Hammersley and Atkinson 1995 p.7). According to these authors this also means that the same stimuli can result in different things at different times for the same person, as well as to different people. Symbolic interactionism is ‘in part’ important to IPA because of interest in the cultural impact on the experiences and sense-making of the participant (Smith et al. 2009).

The aim of the study was to understand parents’ experiences, which could be complex in the context of child growth and development, and could occur over a prolonged period of time. Seeking to understand implies adopting an interpretative stance. From an ontological perspective being interpretivist sees “people and the world as interrelated and engaged in a dialogic relationship that constructs (multiple versions of) reality” (Shaw 2010 p.4). From an epistemological perspective “IPA is avowedly interpretative” in that knowledge is generated by the researcher attempting to make sense of the participants sense making (Smith et al. 2009 p.200). As a consequence of adopting an interpretivist stance the relationship between the researcher and the researched is fundamental to the quality of the data generated. This will be explored further in terms of reflexivity. IPA is strongly phenomenological in origin and thus influenced by its epistemological position.

**Phenomenological considerations**

Finlay (2009, 2012) has written and spoken extensively about phenomenological
methods and states that despite the multitude of methods there is agreement that the “central concern is to return to embodied, experiential meanings” aiming for “fresh, complex, rich descriptions of a phenomenon as it is concretely lived” (Finlay 2009 p.6). Phenomenology originated as a philosophy, distinct but related to ontology and epistemology, with the German philosopher Edmund Husserl (1859-1938) in the early twentieth century. Phenomenology, from Husserl’s school of thought is concerned with phenomenological reduction, description and the search for essence\textsuperscript{14}, while bracketing by putting to one side, one’s past understandings, knowledge and assumptions. His pupil Martin Heidegger (1889-1976) led a move away from the ‘vigorously descriptive’ Husserlian tradition and focused instead on developing a hermeneutic approach which proposed that all our activities are always ‘in the world’ and thus researcher subjectivity needed to be foregrounded. His seminal publication on ‘Being and Time’ marked him as a noted ontologist. From Heidegger’s perspective “we interpret our activities and meanings things have for us” by examining our contextual relationship to worldly things (Stanford Encyclopaedia of Philosophy 2003 p.12). Interpretation from the perspective of Heidegger is a basic structure of being-in-the-world (Finlay 2012). Since Husserl and Heidegger’s era there has been a proliferation of both descriptive and interpretative phenomenological methodologies (Finlay 2009).

In this study I sought to understand parents’ experiences of child growth and development concerns which required moving beyond descriptive phenomenology to interpretative phenomenology with its foundation in hermeneutics. IPA is a relatively

\textsuperscript{14} Essence: “In the eidetic reduction one needs to see past or through the particularity of lived experience toward the iconic universal, essence or eidos that lies on the other side of the concreteness of lived meaning. The idea of phenomenological essence or eidos does not refer to some immutable universal or generalization about human nature of human life.”

new method of interpretative phenomenology originating within qualitative psychology in the UK in the 1990s (Eatough and Smith 2012). From an epistemological perspective IPA is concerned about understanding persons-in-context, which is their relatedness to the world and how they make sense of it (Eatough and Smith 2012, Larkin et al. 2006, Smith et al. 2009). Smith (2004) in exploring the hermeneutic tradition described the double hermeneutics inherent in IPA, as the researcher “trying to make sense of the participant trying to make sense of their personal social world” (p. 40). It was this succinct encapsulation that led to choosing IPA as the methodology considered best to assist in answering the research question.

**Interpretative Phenomenological Analysis (IPA)**

Smith (2004) described Interpretative Phenomenological Analysis (IPA) as having three expansive elements which are an epistemological stance; guidance for conducting research and a quantity of research knowledge. In terms of an epistemological stance IPA can be considered social constructionist, interpretivist and idiographic (Caldwell and Flowers 2009, Larkin 2013, Smith et al. 2009). Therefore, it is more than a method of analysis; it is a recognised method of hermeneutic phenomenology (Finlay 2009). In addition to phenomenology and hermeneutics, IPA is also influenced by symbolic interactionism which according to Gibbs (2012) relates to the meanings which persons assign to events “of central concern, but those meanings are only obtained through a process of social engagement and a process of interpretation” (p. 3). Social engagement in this context could relate to the face to face interviews used to collect data in a study.

IPA is characterised as idiographic, inductive and interrogative. Being idiographic
entails detailed examination of each individual case until closure before moving to cross case analysis. In IPA the inductive stance is foregrounded and is achieved by being open and flexible in relation to obtaining unanticipated data. Being interrogative implies a commitment to using the results to dialogue constructively with existing theoretical literature (Smith 2004). The benefits of IPA include the insight provided into the ‘life world’ and experiences of the individual but a limitation of the method is that it is dependent on individuals being able to verbalise their experiences (Taylor 2012). Quinn and Clare (2008) explored the criticisms levelled at a suggested over-reliance in IPA on language to express meaning. They suggested this should not be viewed as surprising since IPA, like clinical psychology, has strong links with social cognitive psychology. In their view the focus on language may further explain its attraction to health researchers as ‘talk’ is typically used by practitioners and clients to explore, make sense and respond to physical and emotional symptoms. For this reason it is certainly appropriate for use with public health nursing research because so much of the clinical work of PHNs with parents entails verbal interaction (Mulcahy 2002, Mulcahy and McCarthy 2008).

The attractiveness of IPA’s applicability, flexibility and accessibility have, according to Larkin et al. (2006), led to criticisms about rigour and mistaken beliefs about it being the least demanding of the qualitative methods typically used in psychology. In their view this has occurred because of a lack of engagement by IPA researchers with phenomenological origins and theory. Additionally, published studies have been marked by researchers being satisfied with collecting and representing participant voices without developing the analysis to the necessary conceptual and interpretative level (Larkin et al. 2006). A phenomenological emphasis on the claims and concerns
of the participant lies at the core of IPA. After describing ‘what it is like’ for participants the next aim of the IPA researcher is to develop an “overtly interpretative analysis, which positions the initial ‘description’ in relation to the wider social, cultural, and perhaps even theoretical context” (Larkin et al. 2006 p.104).

Smith (2004) suggests that IPA is ideally suited to understanding personal and lived experiences using ‘a holistic lens’ with different levels of interpretation or depth. IPA is also considered by Pringle et al. (2011) to be compatible with the holistic focus of nursing, a view echoed by Biggerstaff and Thompson (2008). They propose that methods such as IPA may be useful in exploring aspects of the clinical encounter particularly the triggers or cues to action originating with patient concerns and leading them to seek help. This is very closely aligned with the aim of this study therefore it was considered a highly appropriate method to answer the research question. Using Larkin et al.’s (2006) analogy I came to an understanding that by using IPA I would not be researching parental concern, rather the person who is experiencing parental concern. I was cautioned however by the variety of authors who suggest that it is a method that is easy to do badly. Therefore I was even more determined to strive for coherence with the methodology and ensure the voices of participants, both described and interpreted were to the fore in this study.

**Study Sample**

Based on the literature reviewed it was beneficial to select a purposive sample varying in age, gender, socio-economic status, ethnicity, age of preschool child, and presenting growth or development concern to ensure opportunities for varied exploration of parental concern. It was desirable from an IPA perspective that there
should be careful selection of participants best able to answer the research question (Quinn and Clare 2008). The study was considered feasible as each Local Health Office (LHO) area had second tier services, which accept PHN referrals in response to parental concerns. Therefore, a purposive sample of parents (n=15) of a pre-school child who had been referred to second tier services in three LHO areas in the south of Ireland were selected. These children of concern were included on the basis of some parental concern about child growth or development, as yet undiagnosed where the initial reason for referral was based on a concern expressed by a parent rather than the HCP.

Smith (2004) suggests that small homogenous sample sizes of five-10 are typical of IPA studies to permit detailed analysis and further state that analysis of a single case is possible. The current sample size is larger than recommended by Smith et al. (2009) but can be accounted for by the fact that the size was chosen to capture the broad range of growth and developmental concerns that could arise. It is acknowledged that with adequate time and resources larger samples have been used in IPA (Quinn and Clare 2008, Smith et al. 2009) and I have made every effort to ensure all participant voices are represented in the following chapter when presenting the study findings.

Despite clear inclusion criteria communicated to the PHN gatekeeper that the concern was parental rather than HCP in origin, it became apparent only during interview that two parents did not meet these criteria. Denise (Participant 2) indicated that the referral was made ‘at their (PHN) behest’ because her daughter Cara was not

---

15 Child of concern is a term used in this study to denote the child relevant to the initial inclusion criteria as it became obvious that some parents had concerns about other children in the family.
growing. In Meg’s case (Participant 10) a referral was made by the PHN at the eight month developmental check because Meg herself had a squint when she was a child. Meg said she had not noticed any problems with her daughter’s eyes and the referral was made solely on the basis of family history of squint. I felt it was inappropriate to end the interviews when these disclosures were made because it was clear that the parents wished to share their stories, but instead probed to ensure my interpretation was accurate. I reflected in depth about the continued inclusion of Denise and Meg in the study. Ultimately I felt it would be unethical to exclude them as they had given their time and informed consent to be interviewed. Some of their data could still be used and analysed and I believe it adds to my understanding overall by hearing the experiences of parents who ‘went along with’ a HCP’s assessment of a child growth or development concern.

Further exclusion criteria used in the study were: if the nature of the concern was a child welfare or protection issue; parents who were pregnant because of the possibility of becoming distressed; or who could not speak English. The latter point presented a challenge in the very first interview with Edwina. Again the PHN gatekeeper was made aware of this exclusion criteria but it became obvious during the interview that Edwina while having good English comprehension struggled with expressing herself with any degree of depth. These experiences in three of the 15 interviews provided valuable learning about the limitations of accessing a sample through a gatekeeper which will be discussed further later.

**Access and recruitment of participants**

Permission to access the study site was obtained from the Directors of Public Health Nursing (DPHN) in the three LHO areas (see appendix 1) to approach PHNs to
identify a potential sample of parents. On receipt of ethical approval (see appendix 2) email or telephone contact was made with at least 20 PHNs known to me, to identify one or two potential participants from their recent referrals. Each PHN was asked to give these potential participants a cover letter (see appendix 3) and an information leaflet (see appendix 4) and seek their permission for me to make contact with them by telephone. With this initial permission for contact obtained I telephoned potential participants and offered them the opportunity to ask any further questions and agree or decline to take part. If the parent agreed to take part arrangements were made to meet in a place of the participants choosing for a consent form (see appendix 5) to be discussed, signed and an interview to be conducted.

It took four months to recruit the sample which was longer than initially anticipated. Twelve participant parents came from one LHO area the remaining three from two other LHO areas. I collected some data on non-participants especially socio-economic status since Smith (2004) suggested that there may be a bias by researchers towards middle class groups in the belief that they possess the reflexive articulate qualities desirable for interview. Seven parents had initially agreed to take part and then either changed their minds or were subsequently not contactable. There was no difference between those who did and did not participate in terms of the types of child growth and development problems causing concern. While there was a socio-economic mix in both groups, none of the participants and three non-participants came from very disadvantaged areas indicating a possible lack of representation from very disadvantaged areas. Representation is not relevant to qualitative studies but this point is made rather to illustrate that I set out to recruit widely from a socio-economic perspective. Further detail about the parent characteristics are provided in
the next chapter showing the variety of parent socio-demographic backgrounds contextualising the idiographic nature of their experiences.

**Data collection procedures**

Semi-structured interviews were used as the data collection method in this study as they are typical of IPA studies. An interview schedule (see appendix 6) was developed from the literature asking parents to describe: their experiences of the origin of their child’s symptoms; the influential factors and how they felt and responded; through to expressing a concern to a PHN which precipitated a referral to second tier services. Heffron and Gil–Rodriguez (2011) recommend that interview schedules should be short, starting with broad questions. Biggerstaff and Thompson (2008) describe the interview schedule in IPA as ‘merely the basis for a conversation’ where ‘the interviewee takes the lead’ (p.8).

Piloting the study methods is an important part of the research process (Maltby *et al.* 2010). While the entire study was not piloted *per se* I was very keen to test my voice recording equipment and interview schedule. Consequently, I pre-tested the data collection procedures with two parents who were known to me. As a novice qualitative researcher this was very useful to hear participant opinion of the proposed questions and assess deficits in interviewing skill that needed to be improved for the main study. This endeavour helped me identify that I had been intent on following the interview schedule rather than allowing the parent to take the lead. A very useful piece of advice in these early stages came from my supervisor to probe participants about ‘what is going on in your head about that’, rather than the more potentially intrusive ‘what were you feeling about that? The latter question was found to be more closed in that parents were inclined to name an emotion such as saying they
were ‘worried’ or ‘concerned’ rather than elaborating on what they were feeling or thinking.

During each interview I made every effort to be non-interventionist as recommended by Smith et al. (2009) in my interviewing style. I used the interview schedule as a guide in the beginning and thereafter let the parent take the lead. I conveyed as much as possible that I was interested in their thoughts on their concern about their child and kept the questioning open about those elements. I only used probes to clarify such as ‘can you tell me more about that’ or ‘why do you think that happened’? I reflected on my approach after each interview by listening to the audio recording for the interview style, the sound of my own voice, and for affirmative utterances. In subsequent interviews I tried to be more open in my style of questioning and replace the many ‘yes’ affirmations instead with non-verbal affirmations.

One interview was conducted on the telephone as this was the wish of the participant, Denise. Another interview took place in a participant’s (Connie) place of work and the remainder took place in parents’ homes at their own requests. Although interviews were not rushed they did vary in length from 14 to 80 minutes. The main reason for interviews being foreshortened related to child care demands, which was to be expected with a sample of parents of young children. The shortest interview had little depth mainly due to the language barrier already outlined, whereas the 15 minute interview had some depth and the 19 minute interview was very reflective so it is not always possible to judge depth by length alone. Smith (2004) believes quality accounts are more associated with the significance of the experience and how engaged participants feel. As I was aiming for deep data (Smith 2011a), careful
attention during each interview was paid to the quality of interview style and consistency of probing as already discussed.

Interviews were audio taped using an Olympus digital voice recorder (Model WS811) which yielded high quality audio data, apart from the one interview which took place by telephone with Denise. In this case the quality was not as clear as I would have liked and although some words were inaudible the information gleaned was nevertheless usable. Field notes were made during, and immediately following interviews, which is in keeping with IPA. It is considered important to make notes on initial thoughts, observations and reflections (Biggerstaff and Thompson 2008, Taylor 2012). Not only did I make contextual observations about the presence of others and their impact, I also made a point of recording the main impression I got at each interview. For example when I interviewed Gina it was my third interview and the first one where I felt the participant was totally at ease and really talkative. My impression was that she was more concerned about her 13 year old daughter rather than the child of concern which was an unexpected finding. The fourth interview with Noelle was relatively short and there was a lot of family activity relating to having recently moved to a new house. However, Noelle reflected eloquently about describing herself as ‘a little bit not sure’ in the way she expressed her concern about her daughter to her PHN, who was packing the baby scales indicating she was ready to leave at the end of a visit. This felt like a ‘eureka’ moment for me and it was expressed right at the end of an almost hurried interview. It, and the previous example reassured and excited me about the value of the research question I was seeking answers to and reinvigorated me to listen carefully to the voices of parents for the richness of their experiences. I felt I was complying with Smith et al.’s
(2009) recommended need to be responsive to participant cues and the opportunities to probe deeper. However these experiences also worried me that I might be grasping at material I wanted to hear. The whole experience reaffirmed the critical value of reflexivity, which will be discussed later and made me more determined to ensure that parents’ voices were to the fore throughout this study.

**Ethical considerations**

According to Maltby et al. (2010) it is vital that nurse researchers do all in their power to uphold ethical principles to protect the moral and legal rights of study participants. Application for ethical approval was made to the Clinical Research Ethics Committee of University College Cork, outlining specific efforts in the proposed study to protect the rights of the parent sample from recruitment through to publishing the findings. In particular, the ethical proposal addressed measures to ensure compliance with ethical principles of autonomy, justice, non-maleficence, and beneficence (Haigh 2008). Expedited approval was granted to proceed with the study (see appendix 5).

Implementing ethical principles in this study meant the parent sample was accessed through a PHN gatekeeper and no direct approaches were made by me until they had given a verbal assent to the PHN to be contacted by telephone. The fact that seven parents who initially agreed and then withdrew indicates that they did not feel pressurised to proceed with participation. One mother, who clearly wanted to take part initially, withdrew later because she said her husband was uncomfortable with her returning to talk about a difficult time in her life. As described earlier, parents were given an information leaflet detailing the study so that they had full information to give informed consent. Further opportunity to ask questions was afforded when I
met parents prior to signing consent forms. A copy of this form was given to each parent for them to keep.

All parents, children and PHNs were given pseudonyms and place names were omitted. These strategies were to protect participants’ identities and ensure confidentiality. Only I have access to the original unedited names, addresses and other identifying details and these are maintained securely in locked cabinets and password protected computers. All files relating to the study will be maintained securely for a minimum of seven years in compliance with research data storage procedures in University College Cork.

I had acknowledged on the ethics application that I may have been approaching parents at a particularly worrying time in their lives in that they were concerned about some aspect of child growth or development. However from the rich narrative data parents provided I believe that they found it beneficial to describe and reflect on their experiences with a view to potentially assisting other parents in the future. No parent expressed any distress during the interview. Most parents expressed interest in the study and a desire to see the findings on completion of the study.

**Analytical techniques**

IPA in addition to being considered a qualitative method is also a method of thematic analysis, although many (Brocki and Wearden 2006, Smith 2011b, Smith et al. 2009) believe that IPA should go beyond standard thematic analysis. In this regard IPA requires that researchers do not stop at identification of themes applicable across cases but rather strive for higher levels of interpretation while retaining idiographic commitment to the individual case (Smith 2010, 2011a). Regardless of the type of
design it is generally accepted that qualitative data analysis has a number of stages commencing with the management of raw data through to its transformation, depending on methodology (Coffey and Atkinson 1996, Maltby et al. 2010). According to Sullivan et al. (2012) it is vital to adopt a clear epistemological position coherent with IPA before beginning the analysis. As articulated earlier I have adopted an epistemological stance that will see me treating participant data as a means of seeking to understand their experiences in the context of their world.

As mentioned earlier the interviews were digitally audio-recorded which facilitated electronic storage, further management and transcription. According to Dresing and Schmieder (2012) the level of transcription detail depends on the method of analysis. Based on these and other experts (Burke et al. 2010, Gibbs 2010) a transcribing convention was developed (see appendix 7) to ensure standardisation and compliance with accepted norms for presentation of narrative data. Transcription was initially carried out using Express Scribe™ software to learn about the transcribing process and then professional assistance was sought to allow time to concentrate on the analysis. Biggerstaff and Thompson (2008) caution that transcription should be meticulous and detailed and this was achieved by firstly transcribing myself and then listening to the audio while checking the professionally prepared transcripts. Reflecting on this process it was useful to have had the time and space to immerse myself in the audio recordings.

Figure 2.1 is a diagrammatic representation of the procedure I identified from a variety of sources and followed throughout the analysis. This shows the stages one to four with each individual transcript before moving to the next participant in stage
five. Analysis occurred concurrently with data collection and started in phase one by firstly listening to the audio recording which I had copied to a Compact Disc (CD) so that I could listen in the car while commuting alone to work. I then typed a page consisting of a descriptive paragraph of what was going on with this participant followed by a paragraph with my initial interpretations. This ensured that my most powerful recollections were recorded succinctly in context. In phase two, initial noting of descriptive, linguistic and conceptual comments was carried out in the margins of the transcripts as described by Smith et al. (2009). Transcripts were initially noted manually and then with increasing familiarity the process was carried out directly on NVivo10™. This approach is recommended by Quinn and Clare (2008) as a way of learning and becoming familiar with IPA. Stage three commenced with identifying emergent themes, staying close to participants own words and phrases. I resisted the temptation with each transcript of ‘shoehorning’ a segment of parent narrative to an existing theme just because they were slightly similar. I wanted each parent’s idiographic traits to remain visible. Stage four entailed a search for connections across emergent themes, assisted by drawing crude line diagrams to illustrate participant stories.
Sequencing of IP Analysis adapted from variety of sources (Quinn and Clare 2008, Smith 2004, Willig 2001)

Smith *et al.* (2009) suggests that researchers should be ‘playful’ and innovative when analysing data. To this end I generated word clouds by inserting parents’ transcripts into Wordle\(^\text{16}\). Wordle has been used previously in research relating to education (McNaught and Lam 2010), and language acquisition (Baralt *et al.* 2011). They are considered very useful for visualisation purposes and as a general aid to content analysis, providing their limitations are acknowledged (Minocha 2010). These limitations relate mainly to the fact that Wordle graphics simply produce frequencies of words and that these words will be presented out of context (McNaught and Lam 2010). I printed each Wordle and had them nearby when analysing so that I would have, not only an auditory memory of the interview in the form of the audio but also

---

\(^{16}\) Wordle is a toy for generating “word clouds” from text that you provide. The clouds give greater prominence to words that appear more frequently in the source text [www.wordle.net](http://www.wordle.net)
a visual ‘interpretation’. These were particularly striking for those parents who spent far longer talking about children other than the *child of concern* because these other children’s names and problems had much greater prominence in the Wordle. For example Muriel spoke more about her older child Darren than Tricia, the child of concern with the result that Darren’s name is more prominent in the Wordle (see Appendix 8).

Stage five is about repeating the process one to four with the next case and it is only at stage six that one looks for patterns of convergence and divergence across cases. I went through four phases of creating, reviewing, modifying, merging emergent themes and grouping and re-grouping them into subordinate and superordinate themes. Various terms and descriptions are used for the hierarchy of themes in IPA. At its simplest, the initial themes from each interview are grouped and clustered to form emergent themes. The next level or group may be called subthemes or sub-ordinate themes. These subthemes are then grouped under a thematic heading called a superordinate or master theme (Quinn and Clare 2008). In terms of the analysis in the current study the pattern of themes became clearer with each iteration until a coherent interpretation of parents’ experiences emerged which will be detailed in the following chapter.

Use of computer software in IPA is considered up to individual preference (Pringle *et al.* 2011). The attraction as the quantity of data builds up is its portability, allowing immersion in the data whatever the location, without the volume of paper associated with manual coding. The ‘messiness’ oft described (Sinkovics and Alfoldi 2012) and lauded by experienced qualitative researchers who prefer manual analysis can still be
present in the volume of data, the multitude of computer files, memos, various linked annotations, coloured fonts and highlighted text. However the use of qualitative data analysis software permitted ready access to data and ensured it all remained cross referenced, thus allowing more time for conceptualisation.

**Methodological rigour**

IPA is considered a rigorous method of qualitative analysis because of its focus on rigorous and systematic exploration of idiographic experiences (Biggerstaff and Thompson 2008). Methodological rigour is critical to advancing qualitative research (Finlay 2009, Koch and Harrington 1998, Morse *et al.* 2002, Smith *et al.* 2009) and has been the subject of much debate over the years. Validity and reliability are terms used to denote quality in quantitative studies but they are not considered appropriate to qualitative studies. Applying traditional quantitative criteria such as validity and reliability to qualitative research has been described as ‘illegitimate’ not only because of differences in relation to what is assessed, but for fundamental theoretical and paradigmatic reasons (Tracy 2010). The lack of a unified theory, methodology and method to describe qualitative research makes consensus on criteria to assess quality in qualitative research similarly problematic (Rolfe 2006). A seminal work by Lincoln and Guba (1985) proposed the concept of trustworthiness concerning credibility, transferability, dependability and confirmability. The only one of these terms used by Smith *et al.* (2009) in relation to IPA is transferability and it was used in the context of theoretical transferability. This concept was discussed from the perspective of rejecting the concept of generalizability as used in quantitative studies and a consideration of linkages instead between the findings and existing literature. Smith *et al.* (2009) expressed a preference for Yardley’s (2000) expansive principles for assessing the quality of qualitative research which are; sensitivity to context;
commitment and rigour; transparency and coherence; impact and importance. Rigour as just described is merely one element of quality, similar to Tracy’s (2010) eight criteria items. Whereas others view rigour as an overarching term to describe ways of establishing trust and confidence in study findings (Thomas and Magilvy 2011).

To analyse my contribution to rigour in this study I have devised a table (see table 3.1) which captures adherence to rigour as proposed by Smith et al. (2009) and Yardley (2000). This table indicates that the strategies undertaken to enhance rigour were interspersed throughout the process and are coherent with IPA.
<table>
<thead>
<tr>
<th><strong>Yardley’s (2000) principles</strong></th>
<th><strong>Smith et al.’s (2009) opinion of factors within IPA which ensure adherence to Yardley’s (2000) principles.</strong></th>
<th><strong>Strategies undertaken to attain rigour in the current study</strong></th>
</tr>
</thead>
</table>
| **Sensitivity to context** | Efforts to access appropriate samples by establishing rapport with key gatekeepers.  
Close attention to interview process – empathising and working at putting participant at ease.  
Sensitivity to the data by immersion and disciplined attention to analysis process.  
Giving participant voice by volume of verbatim extracts | Worked with PHNs known to me to access appropriate samples  
Careful attention to interview process and participant ease with formulating experiences of concerns resulting in depth of data.  
Prolonged engagement with data collection and analysis (see Gantt chart appendix 9).  
Large volume of verbatim extracts in final report |
| **Commitment and rigour** | Degree of attentiveness to participant during data collection.  
Care with analysis of each case  
Thoroughness of the study including sufficient idiographic engagement and interpretation.  
Extracts from each participant or judicious illustration of each theme with larger samples | Focus on each individual participant  
Each case analysed separately in line with IPA  
Attention to Description and Interpretation. Analysis techniques closely reviewed by supervisor.  
Report contains many extracts from participants in text and tables |
| **Transparency and coherence** | Clarity of stages of research in the write-up. Use of tables.  
Consistence with IPA and both phenomenological and hermeneutic sensibilities | Report written-up with close attention to detail. Tables used appropriately.  
Contains description of lived experience and interpretation |
| **Impact and importance** | Is the study interesting, important and useful? | The study addresses a gap in the literature of interest to HCPs and parents. It is important to preventative child health services and the finding will be of use to policy makers, educators and clinicians – detailed in discussion and conclusion. |
Morse *et al.* (2002) proposed that rigour should be a process rather than evaluative undertaking, a view shared by Smith *et al.* (2009) and Yardley (2000). Morse *et al.* (2002) provided an interesting discussion on the subject of rigour. Their argument centred on the varied strategies used to ensure trustworthiness and utility after the research was completed. They argued for qualitative researchers to reclaim responsibility for implementing verification strategies to attain rigour during the research process. These strategies should then be “woven into every step” of the project (Morse *et al.* 2002 p.9). Morse *et al.* (2002) stressed the importance of data saturation and negative cases to address quality generally in qualitative studies but they also stress coherence with the method. These are not elements of IPA and were not used. Rather than focusing on negative cases, Smith (2011b) stressed that good IPA studies demonstrate capturing convergence and divergence in the participants’ experiences. He stated that “good IPA studies tell the reader something important about the particular individual participants as well as something important about the themes they share” (Smith *et al.* 2009 p.181). This indicates the importance of exploring rigour in the context of the specific method used.

As recommended by Pringle *et al.* (2011) every effort was made to adhere to a clear, auditable systematic process. Ample detail was provided in this chapter to describe the methods used. Using NVivo ensured that the analysis process was fully auditable with an event log. Screen shots of various analysis phases are provided in Appendix ten and indeed it would be possible to access the software and undertake an independent audit as recommended by Smith *et al.* (2009). The limited screenshot examples illustrate the large number of themes with which the process started. It transparently records the dates that NVivo nodes were created and subsequently
modified. It should however be borne in mind that analysis is “only ‘fixed’ through the act of writing up” (Smith et al. 2009 p.81), accounting for differences between the early analysis stage and the final thesis. Nonetheless, each theme from analysis can be connected precisely back to participant transcripts, annotations and memos ensuring constant linkages with the participants and the context. Based on Morse et al.’s (2002) argument these audit trail measures while ensuring that an element of rigour can be established after the research, they do nothing to guide research quality during the process. However, if a desire for honesty and transparency lies at the centre of providing auditable analysis, as was the case in the current study, this enhances, as suggested by Tracy (2010), the sincerity and ultimately the quality of the study. The concern throughout the study was respecting the integrity of participant data and carrying out a rigorous interpretation.

Going back to participants using member checking or participant validation can be part of the process of ensuring rigour in various qualitative designs. However member checking is not associated with IPA and was not done in the current study, although it has been used previously with the method (Rizq 2008). Some authors (Carlson 2010, Crotty 1996, Finlay 2009, Koch and Harrington 1998, Morse et al. 2002) have expressed reservations about the value of returning to participants with interpretations of their narratives. In particular from the perspective that they may experience disappointment or distress because they may not readily see their input or not agree with the way it has been interpreted by the researcher. Many parents expressed a desire to see the findings. I believe that participants have a right to see general findings as they gave willingly of their time to contribute to the study and I had given them an undertaking to that effect at the end of interviews when asked.
Drawing on the work of Yardley (2000) on assessing the quality of qualitative research Smith (2011a) developed his own criteria specifically to assess the quality of the body of published IPA studies. In relation to rigour he was quite precise about illustrating the prevalence of each theme and how many extracts per theme should be provided to demonstrate the variability among participants. Smith (2011b) responded to criticisms of this seemingly quantitative recommendation by acknowledging the incongruence and stating it was merely a symptom of the review process he employed, and that ultimately there should be sufficient participant extracts to illustrate plausibility and persuasiveness. Plausibility is achieved according to Koch and Harrington (1998) in research which is well signposted, allowing readers to see the participant’s world and ‘the makers of the text’ (p.887).

**Reflexivity**

According to Maltby et al. (2010) reflexivity entails being able to ‘hold a mirror up’ to the study from the perspective of the researcher’s personal motivation, data production and the social context of the study. They caution that reflection should be done regularly and systematically and not left until the last minute. In line with these recommendations a diary was kept to log progress and reflect on what I was trying to achieve. I regularly reflected both in my diary and during supervision on how much my previous work on parental uncertainty might influence how I approached the data collection and analysis in this study. For example, during the earlier interviews I tried to avoid using the terms ‘uncertainty’ or ‘concern’ during conversations with parents. I listened to the audio tapes trying to identify if anything I had said could be construed as ‘leading’ the participant. For example, Noelle’s reference to being ‘a little bit not sure’ initially led me to casting my knowledge of ‘uncertainty’ to one
side. However, over time I learned to be more reflective with recognition that what was needed was an awareness and acknowledgement of how my perspectives and assumptions may have influenced the data collected and its analysis. Writing and talking about all elements of the process helped keep my perspectives fore fronted and maintained a focus on the voice of the participant.

I was mindful of Finlay’s (2009) caution to reflexive researchers to avoid becoming lost in a ‘navel gazing’ trap and that often the best way for researchers to demonstrate reflexivity is to emphasise the systematic nature and scientific credentials of the final presentation. I was determined to make every effort to let participants’ experiences lead me to the ultimate interpretation. Smith et al. (2009) stressed that paying careful attention to the process of engagement with the participant, ensures their experiences rather than any researcher concerns remain fore fronted.

I was also aware that previous experience could inform the interpretive analysis (Hammersley and Atkinson 1995, Pringle et al. 2011). As suggested by Quinn and Clare (2008 p.382), and bearing in mind my past quantitative research experience I endeavoured to enhance credibility by carefully ensuring results were ‘grounded in the text’ and used ‘participant’s own words as theme headings’ where appropriate. I made every effort to accomplish accounts which were rich and transparent enough to enrich theoretical transferability. I was careful about not losing sight of the idiographic nature of IPA during the analysis and also endeavoured to ensure it was reflected in the final thesis.
My past clinical experience as a public health nurse ensured that the social context of participants’ lives remained to the forefront of my mind in any interaction I had in participants’ homes and thus grounded me in that particular context of the study. While I might have felt comfortable in that context and to a certain extent professionally ‘at home’ I needed to reflect on what Bulpitt and Martin (2010) describe as the ‘self’ as research instrument. This entailed considering the difference between the therapeutic interview and the research interview. In terms of being a phenomenological researcher, Smith et al. (2009) described layers of reflection which needed to be considered. He suggested that participants may have done a certain amount of reflecting themselves on an experience but the researcher may well spark additional new reflections. Furthermore, the researcher will then, during analysis, reflect and comment on the descriptive, linguistic, and conceptual content of data producing almost a layered on layered reflection. The essence of IPA is fully achieving this ‘making sense’ of the participants ‘making sense’ of an experience (Smith et al. 2009). In order to show the reader “what is going on” in the research project, Koch and Harrington (1998) recommend that the researcher be a skilled writer so that the “final research project resembles a thoughtfully constructed tapestry” (p.889). With each successive draft I honed my writing style and included the degree of reflexivity required to enhance plausibility.

**Summary**

This methods chapter opened with a broad research question cogent with IPA (Smith 2004). There followed a rationale for the design, epistemological stance, sample, access, recruitment and ethical considerations. Consistent with IPA, data were collected from a purposive sample of 15 parents of pre-school children using semi-structured interviews. These methods were appropriate to addressing the aim of
understanding the experiences of parents of children referred to second tier child developmental services who expressed a child growth or development concern. I concluded with how data generated by the method, and presented in the next chapter, were analysed using IPA and included a discussion about rigour and reflexivity implications for this study.
Chapter 4: Findings

This chapter presents the findings from 15 interviews with parents. Based on Interpretative Phenomenological Analysis (IPA) four master or superordinate themes emerged. These were: Uncertainty “a little bit not sure”, Parental Knowledge – ‘being and getting in the know’, Triggers to Action and Getting the Child’s Problem Checked out. As background context prior to presenting these themes, two contextual themes regarding the child of concern are presented, namely: The Concern- “telling it as it is” and Referred On. First the characteristics of the participating parents and their children are presented in terms of biographical data. Then there will be a brief description of the individual circumstances of each participant. The remainder of the chapter will be organised around the superordinate themes derived from the detailed analysis as outlined in the methods chapter.

Characteristics of sample

Fourteen parents who were interviewed were mothers and two were fathers. One father (Jack) was joined by his wife Anita who contributed very little. Another pair (Antony and Donna) jointly contributed. Most parents were from Ireland and four disclosed another country of origin. Nationality was not elicited, therefore country of origin was recorded instead (see table 4.1 below). The most common parent age group was 35 to 39 years and the most common family size was two parents and three children. Regarding parents’ occupations, it is evident that social class groups one to seven\(^1\) were represented with the majority from the middle groups, namely; non-manual, skilled manual and semi-skilled manual groups.

In terms of context about the child of concern there were thirteen children about whom parents expressed concerns regarding development problems to a HCP. The children were aged between three and 54 months representing nine girls and six boys\(^\text{18}\). Demographic details on all children are presented in table 4.1 as well as contextual details regarding the nature of the parental concern, referral, diagnosis, and any concerns parents had about other children in the family.

\(^{18}\) Total of fifteen children includes two parents where the HCP first expressed the child growth or development concern
<table>
<thead>
<tr>
<th>Interview Number and Pseudonym</th>
<th>Parental Age Group in years</th>
<th>Living with</th>
<th>Number of children in Family</th>
<th>Country of origin</th>
<th>Mother’s Occupation</th>
<th>Father’s Occupation</th>
<th>Pseudonym of child of concern</th>
<th>Concern as described by parent</th>
<th>Age of child when problem first noticed by parent (months)</th>
<th>Age of child when concern first expressed by parent (months)</th>
<th>Age of child at referral (months)</th>
<th>Age of child at interview (months)</th>
<th>Referred to initially</th>
<th>Seen by second tier services</th>
<th>Primary Diagnosis</th>
<th>Concern about another child in Family?</th>
<th>Position of child in family</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Edwina</td>
<td>35-39</td>
<td>Partner</td>
<td>4</td>
<td>India</td>
<td>Housewife</td>
<td>Unemployed</td>
<td>Anwar ‘language’</td>
<td>12</td>
<td>24</td>
<td>24</td>
<td>24.5</td>
<td>Speech and language therapist</td>
<td>Awaited</td>
<td>Diagnosis awaited</td>
<td>No</td>
<td>Youngest</td>
<td>4</td>
</tr>
<tr>
<td>2. Denise</td>
<td>30-34</td>
<td>Alone</td>
<td>1</td>
<td>Ireland</td>
<td>Retail</td>
<td>Not known</td>
<td>Cara ‘Short for her age’</td>
<td>Always knew</td>
<td>24</td>
<td>24</td>
<td>24</td>
<td>30</td>
<td>Public Health Doctor</td>
<td>Yes</td>
<td>No clinical significance</td>
<td>N/A</td>
<td>Only</td>
</tr>
<tr>
<td>3. Gina</td>
<td>35-39</td>
<td>Partner</td>
<td>4</td>
<td>Ireland</td>
<td>Housewife</td>
<td>Ceramic tiler</td>
<td>Emily ‘Mixes up letters at start of words’</td>
<td>36</td>
<td>45.5</td>
<td>45.5</td>
<td>46</td>
<td>Speech and language therapist</td>
<td>Awaited</td>
<td>Awaited</td>
<td>Yes</td>
<td>Youngest</td>
<td>4</td>
</tr>
<tr>
<td>4. Noelle</td>
<td>30-34</td>
<td>Partner</td>
<td>3</td>
<td>Ireland</td>
<td>Housewife</td>
<td>Plant manager</td>
<td>Ois ‘Knees touching internally’</td>
<td>&gt;36</td>
<td>37</td>
<td>37</td>
<td>42</td>
<td>Public Health Doctor and physiotherapist</td>
<td>Yes</td>
<td>No clinical significance</td>
<td>Yes</td>
<td>Middle</td>
<td>4</td>
</tr>
<tr>
<td>5. Sonya</td>
<td>30-34</td>
<td>Partner</td>
<td>3</td>
<td>Sweden</td>
<td>Customer services manager</td>
<td>Student ‘Favouring one side’ (neck)</td>
<td>2</td>
<td>2.5</td>
<td>2.5</td>
<td>3</td>
<td>Physio- therapist</td>
<td>Awaited</td>
<td>Awaited</td>
<td>N/A</td>
<td>Only</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. Patte</td>
<td>25-29</td>
<td>Partner</td>
<td>1</td>
<td>Ireland</td>
<td>Home Help</td>
<td>Bar Manager</td>
<td>Ananna ‘Leg started to go in and got quite clumsy’</td>
<td>42</td>
<td>48</td>
<td>48</td>
<td>54</td>
<td>Public Health Doctor and physiotherapist</td>
<td>Yes</td>
<td>Hip over flexible</td>
<td>Yes</td>
<td>Oldest</td>
<td>4</td>
</tr>
<tr>
<td>7. Connie</td>
<td>40-44</td>
<td>Partner</td>
<td>3</td>
<td>Ireland</td>
<td>HR manager</td>
<td>Teacher</td>
<td>Nigel ‘Speech delay’</td>
<td>18</td>
<td>24</td>
<td>24</td>
<td>37</td>
<td>Speech and language therapist</td>
<td>Yes</td>
<td>Autism Spectrum Disorder</td>
<td>Yes</td>
<td>Youngest</td>
<td>4</td>
</tr>
<tr>
<td>8. Muriel</td>
<td>30-34</td>
<td>Partner</td>
<td>3</td>
<td>Ireland</td>
<td>Quality control manager</td>
<td>Instrument technician</td>
<td>Fiona ‘Fuzzy eyes’</td>
<td>48</td>
<td>51</td>
<td>51</td>
<td>54</td>
<td>Public Health Doctor</td>
<td>Yes</td>
<td>convergence insufficiency'</td>
<td>Yes</td>
<td>Middle</td>
<td>4</td>
</tr>
<tr>
<td>10. Meg</td>
<td>35-39</td>
<td>Partner</td>
<td>1</td>
<td>Ireland</td>
<td>Employed in Family business</td>
<td>Computer engineer</td>
<td>Evelyn ‘History of squint in Family’</td>
<td>Not applicable</td>
<td>8 by PHN</td>
<td>8</td>
<td>24.5</td>
<td>Eye specialist</td>
<td>Yes</td>
<td>Diagnosis awaited</td>
<td>N/A</td>
<td>Only</td>
<td>4</td>
</tr>
<tr>
<td>11. Kim</td>
<td>35-39</td>
<td>Partner</td>
<td>3</td>
<td>Ireland</td>
<td>Self-employed Engineer</td>
<td>Carpenter</td>
<td>Eve ‘In-tubing and falling’</td>
<td>15</td>
<td>15</td>
<td>20</td>
<td>24</td>
<td>Public Health Doctor</td>
<td>Yes</td>
<td>In-toeing</td>
<td>Yes</td>
<td>Oldest</td>
<td>4</td>
</tr>
<tr>
<td>12. Ella</td>
<td>35-39</td>
<td>Partner</td>
<td>3</td>
<td>Ireland</td>
<td>Nurse</td>
<td>Factory worker</td>
<td>Alicia ‘Problem with balance’</td>
<td>14</td>
<td>24</td>
<td>24</td>
<td>24.5</td>
<td>Occupational therapist</td>
<td>Yes</td>
<td>Awaited</td>
<td>N/A</td>
<td>Oldest</td>
<td>4</td>
</tr>
<tr>
<td>14. Felicity</td>
<td>35-39</td>
<td>Partner</td>
<td>3</td>
<td>Ireland</td>
<td>Nurse</td>
<td>Factory worker</td>
<td>Sarah ‘Leg to one side’</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>42</td>
<td>Physiotherapist</td>
<td>Yes</td>
<td>Antenatal positioning and Plagio- cephaly</td>
<td>No</td>
<td>Youngest</td>
<td>4</td>
</tr>
<tr>
<td>15. Siobhan</td>
<td>30-34</td>
<td>Partner</td>
<td>2</td>
<td>Ireland</td>
<td>Community Welfare Officer</td>
<td>Factory worker</td>
<td>Aisla ‘Problem with balance’</td>
<td>14</td>
<td>24</td>
<td>24</td>
<td>24.5</td>
<td>Occupational therapist</td>
<td>Yes</td>
<td>Awaited</td>
<td>N/A</td>
<td>Oldest</td>
<td>4</td>
</tr>
</tbody>
</table>
Cognisant of the need to be idiographic using IPA I have included a very brief
description of each of the parents and their families. This is presented to introduce
their unique circumstances and add context to the findings.

**Edwina**

Edwina and her family, comprising herself, her partner and children have been living
in the city for three years. Edwina noticed a ‘language’ problem with her youngest
son Anwar when he was a one year old in that it was delayed compared with his
older three sisters. Edwina’s partner is currently unemployed. The family’s ethnic
background is Asian and while Edwina gave a non-verbal impression that she
understood English well enough she did not speak it well and most answers were
very brief. As a consequence her narrative was very short.

**Denise**

Denise is a single mother of Cara who is two years old. Denise works full time and
gave her lack of time and busyness as a reason for having a telephone interview. She
seems to have great family support and child-minder because she mentions them
regularly during the course of interview. The relationship with her ex-partner does
not seem to be very amiable and she describes him as being “under the radar” as far
as involvement with Cara’s upbringing is concerned. In contrast, Denise regularly
attends all health assessments and is very protective of Cara. There was a period of
time when Cara’s growth slowed which prompted the referral. Denise said the
referral was not precipitated by her. Denise describes herself as short in stature and
indicates that it has not affected her life.
Gina

Gina has a very bubbly, chatty personality. She and Derek have been married for years and she says they are very close. They have three girls and Gina describes learning about parenting “as they went along”. They have great support also from their extended families that live nearby. Gina is a stay-at-home mum who is very reflective about the influence that she and Derek have on their children. Gina monitors her children’s development very closely and is immensely proud of their achievements. Her youngest daughter Emily mixes up some letters at the start of her words which is also very like what happened with her 14 year old Erin.

Noelle

Noelle is married to Scott and they have four children. There is a lot going on in the family because their youngest son who is 10 months old and has Down’s syndrome, complicated with cardiac problems. Furthermore the family have just moved into a new house. Noelle uses ‘we’ a lot when talking about herself and her partner and says they are “not the types to fret”. However they were concerned about their middle child Orla whose ‘knees were touching internally’. The extended family are reported to be very supportive, but they live far away.

Sonya

Sonya is from Sweden and lives with her partner George and his grandmother. These living arrangements are a little constraining for the couple but are necessary for financial reasons as George is a student. Aidan is the couple’s only child and Sonya’s family are not nearby to provide help and support. From the age of two months Sonya noticed that Aidan was “favouring one side” (of his neck). Sonya seems quite self-assured and matter of fact and is a regular user of health services.
Pattie

Pattie lives in a new house in an isolated rural area with her partner and four children. Her partner does not seem to be involved in child care issues and Pattie relies on her family who live nearby for practical advice and support. Pattie is very practical and business-like in her approach. She had Developmental Dysplasia of the Hip (DDH) as a child and her brother had a lower limb deformity requiring protracted treated. She noticed with her three and a half year old daughter Arianna that her “leg started to go in and (she) got quite clumsy”

Connie

Connie presents as a very self-assured, articulate, professional woman who was interviewed at her workplace. Connie describes her children and her family as ‘not average’ people. Her two older children are autistic and are described as ‘high functioning’ and the family was not ‘panickers’. Her youngest child Nigel started exhibiting speech delay and other issues that Connie thinks might be ASD. Connie’s partner was hardly mentioned in the interview. She said a number of times that they had ‘choices’ in relation to accessing either public or private services. Connie spoke a lot about her experiences and how they might be different to others.

Muriel

Muriel is married to Noel; they have three children and live in an urban area. She was very welcoming, chatty and reflective. Muriel’s middle child Tricia is the ‘child of concern’ and she complained of ‘fuzzy eyes’ but Muriel was more worried about her six year old son Darren’s behaviour. Noel is very supportive but Muriel indicates that he does not like her theorising or speculating about potential problems. Muriel
has strong ideas on parenting, ‘*doing her best*’ for her children and instilling sound values in them.

**Jack**

Jack is Nigerian and there have been many stresses in the family in the past year as Jack’s wife Anita was mentally unwell. Anita is now on monthly injections and the community psychiatric nurse is attending regularly. There are three children in the family but the oldest boy (from Jack’s previous relationship) is an adult and living away. Social workers were involved with the family and Jack had to take unpaid leave to take care of his family. Jack and Anita noticed their eleven month old son Gerard had a “*hip problem*” and took him to the clinic. Jack is worried about financial issues and getting back to work. Both Jack and Anita make many religious references during the interview and indicate feeling supported by their faith.

**Meg**

Meg and John got married in their late thirties and have one child, Evelyn. They live in an urban area and are both working with Meg being in the family business. Meg is very matter of fact in her approach and not very talkative. They both have extended family nearby but do not really engage with them much about child care issues. Meg had a squint as a child and this family history prompted a referral for Evelyn to an eye specialist. Meg does not have any concerns about Evelyn.

**Kim**

Kim lives in a large house in a coastal town with her partner Jed and three children. She runs a seasonal business from the house and it is quite a bustling place. The family and the business seem to be Kim’s responsibility and her partner is not really involved and things need to be “*pointed out to him*”. Kim’s middle child Alan was
“slow to speak” at two years old. Kim had surgery recently during the ‘off season’ for a problem that had been bothering her for months.

Ella
Ella is a contemplative, professional woman living in an isolated rural area. She has an older daughter from a previous relationship who lives with her ex-partner quite a distance away. She has two children with her current partner Peter who she describes as quiet and ‘grounding’. Her middle child Eve has been “in-toeing” and “falling a lot”. There have been a lot of stresses in the family, unemployment, family separation and serious illness.

Antony and Donna
Antony and Donna are from Poland, they live in a suburban area and there are three children. Donna’s older daughter is from a previous relationship. Donna set up her own business and when Antony became unemployed he decided to stay at home and mind the children. Donna noticed problems with their middle child Oscar when he was 18 months and he has been diagnosed as ASD. They do not have close family or friend support nearby.

Felicity
Felicity is a health professional and her partner Dan works in Information Technology (IT). They live with their three children in a large house in a suburban area. In addition to part-time work Felicity looks after the home and all the child care issues with the help of her family and friends who live nearby. Felicity noticed a problem with her youngest child Sarah’s neck being “to one side” when she was a baby and the problem steadily got worse. Dan is not really involved and goes along with Felicity’s decisions about family health issues.
Siobhán

Siobhán and Scott live in a rural area and got married in their thirties and have two young children. Siobhán is very bubbly and outgoing and Scott is patient and quiet but very involved with the children. There is not much support available from Siobhán’s side of the family so she relies on her child-minder and mother-in-law for child health related matters. The child-minder noticed that Alicia, the oldest child, had a problem with her balance and kept falling over. Siobhán could not see the problem but went to seek help nevertheless.

Background context

Two contextual themes regarding the child of concern namely: ‘The Concern-telling it as it is’ and ‘Referred On’ are presented to provide background context prior to introducing the four main super-ordinate themes in the following section.

The concern –‘telling it as it is’

The growth or development concern that parents described about their child varied. Four parents reported concerns about speech and language difficulties (Edwina, Gina, Connie, Kim). Other parents reported concerns about structural/skeletal or functional problems such as relating to hips (Pattie, Jack), knees (Noelle), feet (Ella), neck (Sonya, Felicity) and balance (Siobhán). Two concerns were about eyes (Muriel and Meg), one about growth (Denise), and another about multiple complex problems (Antony and Donna).

Parents described the concern by ‘telling it as it is’, that is, in terms that were clear to them or “in my own language” as stated by Ella. Specific examples of the use of lay terms included “fuzzy eyes” [Muriel] or “neck to one side” [Felicity] or words with
“a twang in them” [Siobhán]. The lay terms just presented are brief and vivid descriptions. However, brief descriptors were mostly communicated by parents during the interviews within the context of a broader narrative description as evident in the following quotation about a toddler in whom there “wasn’t an awful lot of chat”:

“Alan is 2 and a half, and as you can see there is not much conversation out of him he is a quiet little fella ... he still wasn’t talking at all at (2 year development) stage... and coherently you could understand him. There wasn’t an awful lot of chat but I could understand what he was saying... his first words were, actually like two words together 'inside in' 'cot Tiernan' is in the bed and he is going 'dirty Tiernan’... it seems to be a delayed reaction” [Kim 82-84, 303-305]

Gina similarly provided a lengthy description of the concern she had about her child:

“She (Emily) mixes up like “T” and “C” instead of saying coke she says toke, instead of saying frog she says ‘srog’ and it starts with an “S” ... Well I suppose when she was just trying to pronounce words, you know the way we would say “frog” it always came out as “srog” or you know and like we would say fffff trying to teach her to put the teeth onto the lip and she can do that now because she can do the fffff and then she will stay “srog” you know but from a very early age she has never said the words properly at all. But that is the only word that she would get stuck with the rest of them would speak perfectly in every word” [Gina 10-13, 31-36]

As can be seen from Kim’s and Gina’s accounts of their children’s development, their descriptions relating to speech and language are embedded in rich indicative detail on the nature of concern including a snapshot of related development over time. Within the context of describing their concerns, parents often provided two or more specific examples of the developmental problems such as Kim’s reference above to her child stringing two words together: ‘inside in’ and ‘dirty Tiernan’.

Parents’ concerns about their children were by no means related or isolated to ‘here and now’ development or growth problems. Typically parents’ concerns evolved over time and for many parents new problems had appeared since expressing their initial concern to the Health Care Professional (HCP). Some parents described these
new problems as a sequence of events as if the occurrence of one problem was followed by another. For other parents the occurrence of a new problem was clearly unrelated to the initial problem. For example Kim’s son Alan had undescended testes which she viewed as unrelated to his initial problem of speech and language delay.

For some parents development problems were viewed as being possibly related, for example asymmetry of head/neck and eye from torticollis:

“I am a little bit (worried) because as well last week when I went to (PHN) she said his head is a little bit deformed because he is lying on one side all the time so that is something that won’t be OK if we don’t get it fixed. It might get more flat on one side, so I am worrying a little bit and also that his one eye looks a little bit smaller. So she said like as well because he has been lying on one side maybe it is just not trained up, we are referring for that as well to an eye doctor... So I hope it is connected and there is nothing else” [Sonya 178-183]

Sonya clearly wanted the problems to be related so that she would not have something completely unknown or new to worry about. For some parents multiple problems that were the source of parental concern were described as being obviously related, for example behavioural problems and speech and language delay:

...her sounds wouldn’t have been great, she was actually quite late speaking anyway she used to make a lot of little noises but proper comprehensible sounds she was quite late doing... And then she started biting herself always the same arm and you don’t even have to see her doing it you will actually hear her and it is quite a temper when she bites so I think a lot of that is the frustration of not hearing things clearly [Felicity 484-490].

The above quotations illustrate that parental concerns about their child’s development can be complex as they try to make sense of presenting problems. The complexity of parental concerns is presented later within the superordinate themes. In terms of context however regarding the child of concern it is worth noting that seven parents also expressed a concern about another child in the family. For example Donna and Antony’s initial concern was about Oscar. However they revealed that his sister Amanda seemed to be exhibiting a speech delay:

“...she (wife Donna) does think there is some possibilities that we could be
Parental concern that focused on another child in the family was an important context and it dominated the course of conversation in some interviews.

Parents varied in the timing at which they first became aware of problems with their children. Four time periods were collected for the children of concern, namely: age of the child when problem was first noticed; age when concern was first expressed to a HCP; age of child at referral; and age at interview (see table 3.1 above). Of the thirteen parents that expressed a concern to their PHN, three (Noelle, Kim and Felicity) indicated that the problem was present in their child since birth. For the remaining ten parents, developmental or growth problems were noted to arise typically when the child was aged between one and two years old. The oldest child was four years old when a problem was first noted by the mother (Muriel). Only Jack and Ella expressed it verbally as soon as they noticed it. In the majority of cases this expression resulted in an immediate referral by the PHN to second tier services. Three (Edwina, Gina and Sonya), were still waiting to be seen at the second tier or by specialist services at the time of the interview for this study.

Many parents (Antony, Donna, Siobhán, Muriel, Felicity, Ella) spoke about challenges with their children. It was obvious that the more complex the child growth or development concern the more complex would be the day to day challenges. Any behavioural dimension to the parental concern had the capacity to impact on the whole family causing stress. For example Muriel’s concern about her middle daughter Tricia’s fuzzy eyes caused minimal distress to the family other than the
need to ‘get it fixed’. However her older child Darren turned out to be the main source of stress in the family with “day to day challenges” usually about very small issues and Muriel struggled with managing this: “...So it is tough old going like all you can do is your best ...” [Muriel 591].

Parents described a full array of feelings associated with experiencing the concern about their children, from: not actually worried, not overly concerned, to worry, anxiety, nervousness, hurt, fear, upset, relief, hope, guilt at missing or causing it to the worst possible as articulated by Antony:

“So it was very bad time for our family, our son, because it’s like you are waking up in a different reality, it is a different world” [Antony 103-104]

Parents spoke throughout the interviews about all their children, not just the child of concern, with love, warmth and pride. All these comments were very positive and related mainly to their skills or temperament. Children such as Oscar had quite complex disabilities and his parents Antony and Donna spent a lot of the interview talking about these. However they were very keen that the interview did not end without recalling what was positive and what was good:

“So we can say some good things maybe you know (laughs) Oscar is lovely and I think we should be happy we can help him, because there is so many children and you can’t find any help, you can do nothing... He is handsome” [Donna 967-969]

**Referred on**

At the time of interviewing parents, all had expressed concerns about their child’s growth or development to a HCP such as a PHN or GP and had moved to the context of being referred on to second tier services. Parents spoke about being ‘referred on’ as meaning referral to a second tier or specialist service. Referred on was never expressed within the context of going to a PHN. Within the context of being
‘referred on’, parents described ‘the process of referral’ and ‘waiting for an outcome’.

The process of referral

The referral itself was usually a straight forward process in that the parent expressed a concern to a HCP, and a referral was made to a second tier service, an appointment scheduled and period of waiting occurred. Most parents made no complaints about waiting for the appointments, even though these could take a while, in some cases six months. Connie described being unperturbed by the wait for speech and language assessment: “I am like you know within six months things might have improved” [Connie 31-32]. She was clearly hoping that giving it time would allow the problem to spontaneously resolve. In contrast in Meg’s case the whole referral process was quick and had been completed:

“Well Melissa (PHN) referred me on to some eye person when she was about 10 months and they gave a referral for Dr X which we went to about a month ago and he said yeah, like there wasn't anything so he said to come back in about two years. So that's it” [Meg 18-22]

The types of second tier services that parents were referred to in this study were varied. Seven children were referred to a public health doctor. Speech and language therapy accounted for four referrals. Two were referred to a physiotherapist. One was referred to a psychologist and one to an occupational therapist.

Parents were happy to defer to professional or specialists opinion where a diagnosis had been given and some form of intervention required. In Connie’s case they went regularly for therapy and were then discharged:

“... (we) went into the speech therapy system it was quite good as in we had regular appointments, it was once a month we went, up to recently” [Connie 37-39]
For parents like Ella or Kim, where no further intervention was required re-referral was left open to them if necessary. Parents predominantly used ‘we’ to describe themselves and their child as a dyad going through the process and the therapy:

“we have been to the physio since, through the HSE, and she is giving us exercises and it is all going well, and we will be going back again to see how they go” [Pattie 33-36].

For some parents the outcome was awaited.

**Waiting for the outcome**

For many parents their concerns were not resolved because there was so much still going on with interventions and waiting for follow-up appointments. Five were waiting for the concern to be assessed by a professional expert and potentially diagnosed (Edwina, Gina, Sonya, Jack and Siobhán). Jack and his wife had a concern about their son’s hip since he was 11 months old. They went to the PHN immediately and a referral was made by the Public Health Doctor for an X-ray, but the waiting was challenging:

“now we are waiting for the outcome...whenever we go to the clinic I always want to hear the technician (radiologist) saying everything is OK but unfortunately he would not confirm this. He said they have to do an x-ray which I am not feeling very comfortable, not until the result...We have done the x-ray so we are waiting for the result to know if really /. Because we don’t think there is nothing wrong with him... I am really anxious to see the result...” [Jack 77-80]

Some parents had an opportunity to work on improving the problem while they were waiting, like Siobhán who was waiting for a diagnosis. Her daughter Alicia had a problem with her balance since she was 14 months old and although she had been seen by an OT the problem still persisted. Siobhán was working hard to help her balance improve:

“I took her to a lot of Supernovas and the Monkey Maze19 to build up her steps you know climbing up and down steps...No, even though when she was around the

---

19 Supernova and Monkey Maze are indoor activity centres for young children.
Alicia had also been referred to the S&LT for a speech delay and Siobhán was also working on this:

“Every night now we do a story like so we are working together myself and Scott (partner) as well, we follow the guidelines on the fridge because they told us what to follow ...So I just want her to get to that level you know because they just learn from their parents don’t they?” [Siobhán 334-345].

Others had been seen (Denise and Noelle) and the concern was dismissed as being of no clinical significance and these parents were watching their child grow and develop and the problem was ‘coming along’. Denise said:

“I knew she growing and I could see that ...If she wasn't growing at all then obviously I would be more concerned. I know by looking at her and I know by her clothes you know, just, you know that she is coming along” [Denise 73-77]

Others still had received a diagnosis (Pattie, Connie, Mona, Kim, Ella, Felicity, Antony and Donna) and these parents were ‘in the system’ and helping their children attain their optimum development. Pattie’s daughter’s ‘left leg started going in and she got clumsy’ from the age of three and a half. She had been seen and diagnosed with ‘an over flexible hip’ and Pattie was relieved to have a diagnosis that was not the DDH that she had when she was a child. However she was not too satisfied with conflicting advice received in relation to expected spontaneous resolution and preferred to have something to work on:

“Do you know it wasn’t just a case of oh yeah she will be grand she will grow out of it...I am quite relieved you know, that there is nothing serious there and we have to work on it you know I suppose it is in our hands now to work on it you know. But she is very keen to work on it herself as well. Yeah she is amazing she would remind you to do the exercises... She thinks it is all to be a dancer so. Yeah that is her big thing to be able to dance yeah. We are working on getting the hip right before she goes doing dancing anyway” [Pattie 414-426]

Antony and Donna had a diagnosis of autism and global developmental delay for their son Oscar and were waiting for access to the early intervention team. They were...
glad that at least they were ‘in the system’. In the meantime they were doing a lot of
work on diet and home tuition with Oscar to improve his quality of life:

“What we do know the most important thing is for him to start to speak if he starts
to speak we can actually quite fast start to work on his weaknesses, to improve
them. And maybe even one day he might notice in the future that he is different”
[Antony 843-844]
The contextual themes, ‘The Concern – telling it as it is’ and ‘Referred On’ were the
relatively descriptive elements of parents’ experiences concentrating mainly on the
chronology of events. However the more complex areas were how parents made
sense of the concern they felt and what they did about it. This constitutes the core of
the analysis, namely, the superordinate themes which follow.

Superordinate themes

Four superordinate themes were identified, which were: ‘Uncertainty – a little bit not
sure’; ‘Parental Knowledge – Being and getting in the know’; ‘Triggers to Action’
and ‘Getting the Child’s problem Checked Out’. A diagrammatic representation of
these is presented showing the super-ordinate themes, the subordinate and emergent
themes which formed them (see figure 3.1).
Figure 4.1 Diagrammatic representation of themes

Diagrammatic representation of emergent, subordinate and superordinate themes

Experiences of Parental Concern

Getting the child’s problem checked out

Uncertainty - ‘a little bit not sure’

Appraising the concern

Wondering about the cause

Puzzling - ‘is there something wrong?’

What caused it

Watching for a while

Making comparisons

Assessing the child doing other things

Triggers to action

Usual disposition

Seeking affirmation

Seeing the child’s vulnerability

Time passing

Panicker

Non-panicker

Partner/Other

Religion

Impact on the child

Others noticing the problem

School

Give it time

Parental knowledge

Seeking information - just Google

Information from internet

Being and getting in the know

Always knew

Had no clue

Experience with public services

Better safe than sorry

Concern mentioned in passing

Experience with private services

Just check it out

Getting into the system private or public

Professional validation

In the hands of the professionals

Therapeutic Relationships

Emergent Theme

Subordinate Theme

Superordinate Theme

Legend
Smith et al. (2009) suggested that the prevalence of the various themes should be evident for illustration and credibility purposes. Therefore screenshots from Nvivo are provided showing all themes (see appendix 11). It is evident from this that all emerging and subordinate themes are well represented across the 15 parent sources. Within each superordinate theme a table is provided in an appendix to illustrate each theme with segments of narrative. Tables such as these are a feature of IPA (Smith et al. 2009) and serve to provide transparency about the development of master or superordinate themes.

**Uncertainty “a little bit not sure”**

Mothers usually spent time assessing the problem before they considered expressing their concern outside the family. The super-ordinate theme ‘Uncertainty -a little bit not sure’ describes the process of parents initially ‘Appraising the Concern’ and then ‘Wondering about the Cause’ both of which are subordinate themes. Appendix 12 illustrates the superordinate, subordinate and emergent themes in tabular form.

**Appraising the concern**

The subordinate theme: ‘Appraising the Concern’ encompasses four emergent themes which were: ‘Watching for a While’; ‘Making Comparisons –Barometer’; ‘Assessing Child Doing other Things’; and ‘Puzzling – Is there something wrong’.

**Watching for a while**

Parents described how their concerns were laden with uncertainty resulting in closely observing their children over time to make sense of whether their concerns were

---

20 It is noted that further conceptualisation took place during the writing up phase of this chapter which would account for changes to theme names and merged themes from the initial analysis as it appeared in NVivo.
legitimate or not. The following quotation from Pattie illustrates this uncertainty and why she engaged in ‘watching for a while’:

“No I was kind of watching for a while. I was saying is it my imagination or is there something here you know ....” [Pattie 41-44]

For some parents ‘watching for a while’ was complicated by their child’s age, making it difficult to determine with certainty if a problem actually existed:

“...like I was kinda looking but, it’s a case that she was too young really, they were saying the bridge hadn’t formed, so at this stage she was too young to notice so” [Meg 13-16]

‘Watching for a while’ through close observation to see exactly what their child was doing developmentally was evident in parents’ accounts. Some parents described their observations in very specific detail indicating that knowledge of and greater certainty about their child’s problem accumulated with time. For example Felicity described her child’s neck problem as follows:

“Usually she would just kind of be down like that (demonstrated) you know facing down, she wasn’t really able to get up very well because she didn’t like to use her arm, because it meant that she was having to stretch then you know...and she moved alright like she actually got around quite quickly you know she managed to do it but it was always going the opposite, just the one direction you know” [Felicity 287-294]

The increasing sense of certainty that some parents experienced by ‘watching for a while’ was also evident in Connie’s description of gross motor development concerns as well as speech and language delays in her son Nigel:

“So that was very obvious as well, he wasn’t off balance but he was very much walking on his tippy toes” [Connie 143-145]

Similar to the descriptions of developmental problems in the above quotations, parental observations mostly related to watching and noticing overtly visible problems. In most cases problems were suspected in the first instance by parents. However, in some cases, a possible problem was brought to their attention by
someone else, including the child of concern which was evident in Muriel’s account with reference to her child telling her she had ‘fuzzy eyes’:

“I actually haven’t heard her say she has fuzzy eyes since and it used to be every second morning so I was thinking it was sleep in her eye or something. I was like how many fingers is Mommy holding up (laughs) I was trying to do my own eye test, what does this say? ...I was watching that because I was beginning to think it was only the mornings and it wasn’t I think as I studied it more and took in she actually could say it at any time...” [Muriel 51-55]

Muriel’s description of ‘watching for a while’ illustrates how she actively engaged in direct assessment of the problem because of her uncertainty about whether her child’s ‘fuzzy eyes’ were normal or not. Direct and on-going assessment of a child once a problem was suspected was commonly described by parents and some such as Siobhán spoke about enlisting others to undertake this assessment by watching their child:

“I usually ask my child-minder to keep an eye on her like and how many times a day would she fall...” [Siobhán 68-71].

Making comparisons – “Barometer”

All parents made some degree of comparison with other children in their search to make sense of the presenting developmental problem. They compared their child with other siblings, when there were older or even younger children in the family, but also with relations or friends’ children.

“Measuring up … Yeah. I have one niece on my own side but she is only ten months, so, and my partner…has about five but they’d be kind of varying in ages like, but she’s got two alright that are a year older. But the way I look at it is that that is what she’ll be doing in a year’s time” [Meg 63-71]

When trying to assess their child’s development, parents such as Kim, Donna and Connie compared their children with siblings, using the comparison as a ‘guideline’. For example Donna compared her then 18 month old son Oscar’s speech and language about whom she was concerned with her oldest daughter who she described had spoken earlier. This comparison served as a ‘barometer’ to deal with her
uncertainty about whether Oscar had a speech and language problem. In Donna’s case making comparisons helped to establish with greater certainty differences in developmental patterns between her child of concern and her older daughter. In contrast, for some parents, identifying similarities between the child of concern and siblings alerted them to believing their child of concern did have a developmental problem, although not necessarily with absolute certainty. Connie explained how her son Nigel started behaving in a similar fashion to her older boys who had already being diagnosed with ASD:

“We recognise some of the signs. He (Nigel) is very much reminding us of our older child who has Aspergers...a little bit of jumping up and down, arms flapping” [Connie 152-156]

Connie described this as a ‘red flag’ or ‘high alert’ because:

“…I just think that there is so much evidence that it runs in families, we almost should be on high alert” [Connie435-444]

Supportive comparisons were sought with relative’s children especially if these parents had the added perceived expertise of being in a health or allied health profession. For example Denise’s sister was a nurse and Kim’s sister was a social worker:

“My sister is actually quite up in social work. She deals with cases and she wasn’t a bit concerned (about Kim’s child). Her second child did the exact same and even now at four and a half it is hard to understand him” [Kim 125-129]

Although parents made comparisons with other children of different ages, the age differences seemed to make comparisons problematic. Comparisons with other children was easier for parents when their child of concern was attending a toddler group or was the same age, because then: “it was very easy to compare” [Connie 13-14]. Similarly, Sonya commented that: “…I look at other babies to see if they have exactly the same size of their eyes or not (laughs)” [Sonya 242-243].
Comparisons with children of similar ages seemed to offer parents a more definitive perspective that their child did in fact have a development or growth problem. As highlighted by Denise in the following quotation, making comparisons with children of similar ages and what might be expected in clothes sizes offered her a sense of certainty in knowing her child was small:

“Well I knew she was small in comparison to those around her ...definitely when she was hitting two she was fitting into size 12 to 18 (clothes size), they would have been long but not as much. Certainly that would have been the biggest barometer or standing by the television I would have known by the height” [Denise 81-84]

The importance of peer norm reference group to parents in helping them deal with uncertainties concerning their child’s growth or development was highlighted by one mother, Muriel. This mother commented on how working with groups of children of similar ages made it easy to make comparisons between them regarding growth and development patterns. She was talking specifically about staff in the pre-schools:

“he (Darren) did 2 years in preschool and they are very good at watching out for things, they have 30 children they are comparing everybody so it is fabulous they can really see if there is anything standing out” [Muriel 686-689].

Some parents made a point about making comparisons being unhelpful in addressing their concerns because all children are different in how they develop, yet most parents made comparisons. However some parents (Noelle, Ella and Felicity) were particularly uncomfortable with comparing their child of concern with other children and they commented on making every effort to avoid making such comparisons.

However, their descriptions of avoiding making comparisons indicated that this might be practically impossible to do:

“Do you know like especially with an older sibling I think it is very natural to compare... Not really (outside the home) I suppose because again I don’t know, is it just myself and my partner maybe I don’t know, do we close our eyes to a lot of things? I don’t know but we are firm believers that every child is different, they all do things differently...So we don’t fret about things like that...The only thing that we would do I suppose is that without meaning to is compare with her older sister,
because we would be saying ‘oh at this age Amy was doing this and Olive is not or something’ …But that’s it, but outside no, we wouldn’t compare. Definitely wouldn’t because every child is different [Noelle 194-208]

As can be seen from Noelle’s quotation, making comparisons with other children, especially one’s own children is a ‘very natural’ thing to do in helping them to make sense of their concerns about a child’s growth or development problem, even ‘without meaning to’. Ella similarly believed that all children are different and she was very keen to distance herself from making comparisons between her child of concern and other children. In contrast to Noelle who naturally fell into making comparisons, Ella described how she purposively and actively talked herself out of this, as illustrated in her narrative as follows:

“No I don’t at all (compare with children outside) to the point where I have a friend who would have a little girl a couple of weeks younger than him and we would be very close friends…To the point where I would talk myself into not looking or comparing. Not from the point of view that I am worried. She (friend) was constantly comparing weights, and ‘what is she doing now and is she climbing the stairs?’ and it put me off but it is a pointless exercise…Do you know kids are different so I wouldn’t. Even actually her little girl who is four weeks younger than Tim would be a lot bigger, so I don’t even go there. Kids are different, parents are different you know. Eve is very ahead of herself with her speech in comparison to other kids… I was surprised actually at my friend who did because she is normally a very rational girl altogether and very sensible she is a midwife actually and as solid as you can get but would have been very much comparing the two for the first six months or so, whether it was like that hormonal or what I don’t know… Myself and Peter (partner) would both be small, we’re not going to have big kids, so I just don’t, not at all…and even with Amber in secondary school or having her gone through Primary School I would never have asked her how are the rest of the kids in school getting on, I wouldn’t ask their Moms or Dads or I wouldn’t allow questions I would avoid that. I don’t compare, sure everyone is different” [Ella 520-539]

Assessing child doing other things

This emergent theme relates to parental assessment of their child’s progression within the context of both the presenting problem of concern and the child’s general development. The emergent theme of parents ‘watching for a while’ as presented above involved focusing only on the child’s presenting problem. Whereas
‘Assessing the child doing other things’ started for parents within the context of the presenting problem, but evolved into assessment about improvement or deterioration of that problem together with assessing other domains of development or growth patterns in their child. Some parents described little or no improvement with the presenting problem as noted by Gina in relation to her four year old child’s speech and language problem in the preceding two year period: “...so I would say since she started talking this hasn’t corrected itself...” [Gina 37-38].

Parents’ assessment of their child of concern was holistic in terms of taking account of multiple aspects of development. For example Siobhán’s assessment of her 14 month old child was described as follows:

“She is actually getting better now ...improving now... She can walk down the stairs now just holding onto the bannister... So everything is kind of coming around ...That’s it like and her words will just come now, new words are coming every day” [Siobhán 551-558].

As can be seen in Siobhan’s quotation, assessing a child’s development is complex as parents make sense of their experiences of identifying a problem within a broader context of the child ‘doing other things’ developmentally. This complexity of assessment was seen not just for parents who believed that their child of concern was improving, but also for parents who believed their child’s specific developmental problem was not improving compared to the child’s ability ‘to do other things’. For example Antony found in relation to his four year old child that:

“...there is no progress with speaking at all so he stays in the same position; he is improving with other things but not with speaking so we are still waiting for some kind of good signs...” [Antony 827-829]

Antony’s description of assessing his child ‘doing other things’ draws attention to parents attempting to fit various pieces of their child’s development together. The
analogy of the jigsaw depicting pieces of development coming together was described by Ella as she reflected on improvements in her two year old child:

“...and since she has started to be able to put sentences together and tell you exactly what she wants and when she wants it there is a huge improvement in her behaviour and it kind of feels that the jigsaw is falling into place and the walking is improving too...my sister-in-law (a physio) would have said you know she will grow into her bones and grow into her body, and like I said she did grow into herself, it was like the jigsaw went together for her” [Ella 160-168]

Parent’s assessment of all aspects of the child’s development was to reassure themselves that at least the child was ‘doing other things’ developmentally. Based on their assessment of the child, parents were then relieved that they only had to worry about the initial problem they had concerns about. As noted by Jack who said that apart from Gerard’s hip problem: “...he is fantastic there is nothing else to worry” [Jack 152]. Likewise Sonya clearly articulated that if her son was ‘doing other things’ then it was unlikely that he had some kind of a developmental ‘defect’:

“I mean not really worried because I saw he was moving both arms and legs so he was fine but I was just thinking basically for development when he starts crawling or sitting maybe he would be kind of weaker in one side that is what I thought...so since he is moving and everything I don’t think he has a defect or anything” [Sonya 35-37]

It was evident from parents’ accounts of assessing their child ‘doing other things’ that this process helped them in making sense of the concerns they had about their child’s developmental problem and their experiences of uncertainty regarding these concerns. Like the ‘jigsaw’ analogy, when parents became aware of concerns about some aspect of their child’s development they believed that there was a developmental piece missing. They tried to figure out this problem as a way of appraising their concern by trying to fit as many pieces of development together as if working on a puzzle.
Parents puzzled about the child’s problem that they were concerned about which involved thinking about it, wondering about what it was, and worrying that it might be something serious such as a developmental disability of some kind. For example Donna’s puzzling was articulated in her description of how her mind was occupied by her son Oscar’s repetitive behavior with the wheel of a toy car:

“And I don’t know why I actually don’t know why it came into my mind you know and I was thinking that autistic children sometimes I know they do that and it was just you know something like you know that came into my mind” [Donna 283-285]

Similarly Jack was wondering and had difficulty understanding why Gerard might be delayed standing and walking: “I don’t understand why he cry [sic], always scared of standing on his own” [Jack 99-100]. A few parents had hinted at what they were worried about in terms of the potential seriousness of the problem but only he said explicitly what this was: “Well I am scared of having a handicapped child” [Jack 5].

It was apparent from parents’ accounts of their experiences of appraisal of their concerns through puzzling about their child’s development or growth problems that uncertainty prevailed. As described by Noelle “I am a little bit not sure on this” [Noelle 311]. Pattie elaborated on her sense of uncertainty as she puzzled to make sense of her child’s developmental problem:

“I thought ‘mmm’ I don’t know...It just didn’t feel right...I can see myself that as soon as she is in bare feet ...the arches are completely down to the ground like, do you know” [Pattie 276-284]

Even Connie’s efforts at displaying confidence were laden with uncertainty: “But we are in the know and we are little bit kind of like sure we might as well refer him we have nothing to lose by referring him” [Connie 161-163]. Or another parent Ella who was trying really hard not to puzzle, as logically there seemed a reasonable explanation for her daughter’s in-toeing and falling. Therefore there should be no
reason to puzzle that there should be anything further wrong:

“And you would say to me what in God’s name is wrong with you. If Peter (partner) walked in the door his two legs are chapping off each other and his mother would have had him in start rite shoes from a very early age. It is just ...I think it’s hereditary” [Ella 365-369].

Ella’s use of ‘you’ is quite telling in that she is suggesting that an outsider may feel there is a perfectly logical reason for the in-toeing too, given the family history but she is just not convinced by this. Donna described this eloquently as having a feeling “only that you don’t want to believe, you keep a distance...” [Donna 316], almost like keeping fear and puzzling at a distance or arm’s length.

**Wondering about the cause**

In this recurrent subordinate theme parents described going a step further trying to figure out what caused the problem with their child. They wondered whether the problem was associated with something they did or did not do? Parents’ descriptions of the cause of their child’s problems varied and were often embedded in lay beliefs. For example Gina wondered why her daughter Emily had speech and language difficulties when she had decided not to give her child a soother. She compared this to her sister’s excessive use of a soother with her child and had made the link herself between excessive soother use causing dental problems and consequent speech problems:

“But I don’t know is it like Emily never had a dodi or dummy or a soother and my sister’s one has two of them. One in the mouth constantly and one for comfort to be rubbing off her nose...and if their teeth are affected then you know isn’t there speech affected like?” [Gina 153-163]

Muriel wondered if her long and difficult labour affected Darren’s behaviour. Sonya thought lack of space in the womb made sense as a cause for Aidan’s torticollis. In Jack’s opinion Gerard’s hip problem was related to use of a baby walker:

---

21 Start rite shoes are a well-known brand of professionally fitted children’s shoes.
“I used to think because of this walker maybe that is delaying him from walking...he moves very fast but when you move him he can’t stand on his own” [Jack 93-94]

Antony and Donna said their ‘conspiracy theory’ was that the MMR injection caused Oscar’s autism and they agonised about this. They said they knew that there was no evidence for the causal link between MMR vaccination and autism but wondered how the rising numbers of autism in the world could be explained. These parents also believed that candida albicans in the gut was implicated in autistic behaviours and they said the improvements they had witnessed since changing Oscar’s diet were proof of this. Additional causes that parents attributed to their child’s development problem included ‘middle child syndrome’ [Kim], or ‘tiredness’ in the case of Tricia’s fuzzy eyes [Muriel], too much parental attention resulting in behavioural problems [Siobhán], or too little parental attention resulting in speech problems [Kim]. Parents’ desires to assign a cause to the developmental problems indicate their intense need to know why a child development problem happened. Indeed, one parent Connie spoke about volunteering for research advertised on an autism website saying she was a ‘perfect candidate’ because she had three children with autism.

**Parental knowledge – ‘Being and getting in the know’**

‘Parental knowledge’ was found to be a factor in influencing parents’ experiences of being concerned about their child’s growth or development. In this superordinate theme parents described the knowledge sources that they had and used in helping make sense or reducing the uncertainty of their child’s growth or development problem. The two subordinate themes were called ‘Being in the know’, and ‘Seeking Information – Just Google’ (see appendix 13).
‘Being in the know’

The subordinate theme ‘Being in the know’ captured parents’ accounts of knowledge that sometimes varied for different parents. ‘Being in the know’ evolved from experience of making sense of the problem itself, either directly with the child of concern or with another child in the family. Knowing the family history was helpful for some parents (Ella, Pattie, Meg, Kim, Connie) in formulating an opinion about the problem as richly remembered and described in Pattie’s case:

“…Mine (DDH) was picked up at a year and a half and it was kind of accidentally picked up really …then my brother was kind of clumsy and like when he would be running it was like his feet were in like that you know, and he also looked like he was going to trip and Arianna (daughter) had that as well. Not so much obvious in the feet it was kind of more all the way down her legs you know what I mean, that the knees were nearly touching as well... I had 2 operations myself because the first wasn’t successful and I think I was nearly four by the time it was all finished which was a long time... I had the straps and the bars… some one that doesn’t have that history might just walk away from it and say nothing... so I suppose if I hadn’t that history then yeah she would have been:/ …I remember my brother’s feet, because he had been six years younger than me” [Pattie 91-96,131-135]

Siobhán in contrast to Pattie above had no frame of reference to guide her and described herself and her partner as ‘not having a clue’ about parenting generally and specifically about the problem of her daughter’s excessive falling:

“I never noticed it because obviously she was my first child and I hadn’t been a parent before ... I felt it was very hard for me (to know) because every child falls ...You would be thinking you know, I don’t know what it is. When I had Alicia, Nadia (PHN) used to come out and visit me once a week …because I didn’t really have a clue what I was doing and she helped me wash the baby and to change the baby and to tie her down and make sure she has enough blankets and take off blankets. My partner would be a very quiet man like, so we are learning ourselves you see. ...I mean I personally can’t see it (the problem) but I suppose my child-minder and my mother-in-law have more experience than I do” [Siobhán 22-231]

As illustrated by Siobhán, for parents who described themselves as ‘not having a clue’, they relied on others ‘being in the know’ such as their child-minder or family member experienced in caring for children. Being a first time mother was recognised to be challenging in terms of being certain about recognising problems. For example
Connie described how she did not know any different and she did not have a clue on her first child but “I have a clue (now), because it is my third child” [Connie 382]. Muriel, Gina and Siobhán all described similar opinions and said their younger children were reaping the benefits of mistakes they made with their older children: “…so the others are getting our experiences now” [Muriel 622]. For these parents it was evident that knowledge came from experience which in turn influenced their confidence in understanding child growth and development. Felicity said we “know our kids like, don’t we” [Felicity 798] because for her that encapsulated the experiential knowledge that came from parenting.

Gina reflected on the trauma she perceived for her oldest girl Erin with undiagnosed dyslexia all throughout her childhood to secondary school. In her opinion her little girl Emily was exhibiting the same speech pattern as her older sister. Gina believed that Erin ‘fell through the net’ because ‘she didn’t have a clue’ or know about what was going on:

“poor Erin I would describe as being our guinea pig in this house because we hadn’t a clue what was going on, we were only 25 when we had her, whereas now we are hitting 40 and I often would say today like you can see the signs as you are going through school you know of she couldn’t pick up letters, she couldn’t pick up sounds … am I going to go through the same thing that I went through with Erin and then you know but obviously I will be able to pick up and you know she won’t fall through a net …and like Erin now is getting the education we say that she deserves” [Gina 353-376].

Therefore Gina was not going to let the same thing happen with Emily and she was determined to find out what was going on by seeking further information.

Seeking information – “just Google”

Most parents described talking to their parents, partners, sisters or friends about the child’s problem in an effort to seek more information, such as Muriel saying:
“I would talk to family a lot and get reassurances from everybody else saying ‘I think you are on the right track I think it is just the type of child he is’ ” [Muriel 676-678].

However these accounts suggested informal conversations. Actively seeking information about the child growth or development problem, from the internet, TV, books or elsewhere was also described and there were divided opinions about doing this. Both Antony and Donna were regular users of the internet, akin to digital natives[^22], and used it to search for a diagnosis to explain the symptoms their son Oscar was exhibiting and ‘stick them to him’ [sic], resulting in a label of autism:

“…I started to research and there was like one child has this speech and stop, it maybe autism as well” [Antony 368-369].

Similarly his wife Donna described her experience of searching the internet for knowledge as a way of establishing the nature of her child’s problem:

“…if you look on internet and there is few different factors you should look at and I was trying to find them to stick them [sic] to Oscar and sometimes it is really because you can’t imagine what is it actually about you know…I was trying to think if it really is what Oscar does you know, and it was like you know 50/50 for me. So I said if is 50/50 I have to check you know” [Donna 343-350]

Donna and Antony used social networks like Facebook to source other people who may have knowledge or throw light on their child’s problem. They did not describe online support groups of other parents as particularly helpful and preferred instead to ‘just Google’ to search for answers for particular questions:

“…just Google…and check and there is like lots (of information) everywhere if you only know. Just Google, it takes a second…So the thing is you know it will be really good if you can go to some place (website) I don’t know and they can help you what to do you know because all we did was research on internet” [Donna 929-934]

In contrast to Donna and Antony, another couple Noelle and Sean were adamant that the internet was not their preferred source of knowledge, in trying to make sense of

[^22]: A digital native is a person born or brought up during the age of digital technology and so familiar with computers and the Internet from an early age. [http://oxforddictionaries.com/definition/english/digital%2Bnative](http://oxforddictionaries.com/definition/english/digital%2Bnative)
their concerns about their child’s development problem relating to ‘knees touching internally’. Interestingly however, their strong views against sourcing information on the internet was based on their previous experiences because it was clear that they had tried this in the past, but with detrimental results in that they were left ‘scared half to death’ by the information they retrieved. As a consequence of their negative experiences of using the internet to source information, they described that instead they actively asked questions of professionals on a ‘need to know’ basis:

“…we have had a few experiences in the past with other things where we have gone onto the internet and looked and scared ourselves half to death…So we are kind of firm believers if we need to know we will be told it and that’s our philosophy… We did learn the hard way, we will ask the questions we will always be inquisitive but we don’t go onto internets or books or anything, we feel we are asking the experts… So if they tell us what they need to tell us then we are happy to go with that, but we definitely don’t sit by quietly we ask our questions but we don’t delve into it” [Noelle 127-136]

Although some parents such as Donna and Antony seemed keen to ‘delve’ into Google to seek information, other parents such as Noelle and Sean were hesitant. It was apparent from parents that they believed that some problems such as autism were conducive to seeking information on the internet other problems were not. For example Pattie said that she used the internet for various health problems but this resource was not helpful to her to know if her child Arianna’s hips and legs were abnormal because of difficulties for her in making comparisons by looking at diagrams. She spoke of needing a professional assessment to confirm her child’s problem:

“…I know other health things for kids yeah I would look at the internet but for that I wouldn’t, no, I just think it would probably show me a diagram the same as: / and again you are going to be going -is that my child or isn’t it you know” [Pattie 222-226]

It is evident from parent accounts that they acknowledged the limitations of knowledge from the internet to relieve their uncertainty. However in Donna and
Antony’s case they seemed driven to that source because of lack of information forthcoming from professionals as will be discussed later.

**Triggers to action**

Parents rarely described just one trigger that prompted them to take action in addressing the concern formally with a HCP. More often than not there was a combination of: ‘Usual disposition – to panic or not to panic’; ‘Seeking Affirmation from Family’; ‘Seeing the Child’s Vulnerability’ and ‘Time Passing’. A number of emergent themes influenced the development of these subordinate themes which are presented in tabular form in Appendix 14.

**Usual disposition – to panic or not to panic**

Parents described in detail their usual disposition with reference to how they reacted generally when dealing with child health related concerns. Their accounts were particularly insightful in understanding how quickly they acted on concerns. For the nine parents who described their usual disposition three categories of description were identified. These were ‘non-panickers’ (Connie, Mona, Felicity and Kim), those who described panicking about a child development concern (Gina and Ella) and those who were more measured in their responses (Sonya, Siobhán and Noelle).

The non-panickers described themselves as quite laid back and were happy to ‘let nature take its course’ within reason, or ‘let them grow out of it’. They sometimes needed a push to action as described by Felicity and Kim:

“I think it was Breda (PHN) that pushed it a little bit more than me sitting back a bit” [Kim 231-232].

Kim had been happy to wait and see regarding Alan’s speech and language delay but when the PHN noticed the problem as well at the clinic the problem was
acknowledged by Kim and the referral made. Although Muriel, Felicity and Kim all said they were not panickers, Connie in particular was very insistent on describing herself as a non-panicker. She also included her partner as a non-panicker in her analysis. She admitted that this attitude was a bit ‘lackadaisical’ but that they were not really ‘average people’:

“And I am the kind of person that wouldn’t have bothered with the two year check-up unless I got called I would have gone, (if) I hadn’t got called I wouldn’t have pursued it. Unless I thought that there was something wrong...Because it is my third child I am not a panicker anyway and I am like you know within six months things might have improved... so we are not like oh my God you know he definitely has it (autism)...I was very much willing to give it time. I think everybody develops at a different rate, you can’t compare, let’s not panic until there is something to panic about...” [Connie 82-96, 313-314]

The approach taken by Connie contrasts with a more proactive approach of Sonya and Noelle who indicated that if there is a problem they just go and check it out.

Parental experience was not a feature as it was Sonya’s first child and Connie’s and Noelle’s third. In Sonya’s description her actions had more to do with the ‘kind of person’ she was or her usual disposition:

“Yes I am that kind of a person if I see something I would follow up I can’t just let it go I have to make sure it is fine before :/ (Laughs)” [Sonya 195-196]

For some parents their reaction related to the nature of the child’s developmental problem and how visible it was. Gina, already identified as being a non-panicker described this very eloquently. She indicated how fear about a squint triggered complete panic and immediate action whereas a speech delay was almost seen as a variation of normal. The urgency of being referred to a specialist service is illustrated in the following quotation:

“...At one stage when Erin was small they thought that her eye was a bit turned in and I was panicked completely over that you know... I was sick, sick because I thought what is going to happen now is she going to have to have a Patch, will she need glasses? Whereas the speech I don’t know I think it is just a natural

23 Adjective meaning lacking enthusiasm and determination; carelessly lazy: http://oxforddictionaries.com/definition/english/lackadaisical
progression that, that is the way they are going to begin like. They start to talk 'gobbly gook' then you are correcting them, then get their good words and then OK right maybe they are missing, you know but I don’t know like. ...Well she was actually born face down so the nose was squished a bit more on one side than the other so the eye looked as if it was turning in, but actually Derek's sister has a bit of a turn in her eye and I was just panicked completely... I thought I would never get the appointment and I actually thought, will I just take her private and get her seen to because I was panicked completely and even going (to the hospital) when he (doctor) came out and he said you know, no, it is because the bridge of her nose needs to come up into a point I thought, whoa, relief you know” [Gina 282-306]

Gina’s account of going into a complete panic when she thought her daughter had a squint was notably different to her more measured reaction in response to the child’s speech and language concerns. This finding suggests that parents’ fears can be heightened by the visible nature of the problem. If they believe their main concern about their child’s development is an observable problem then that needs to be seen by an appropriate healthcare professional.

Ella spoke of differing responses to her emotional state at a particular time. She described herself as very self-aware and reflected very deeply on why she thought her coping mechanism was very different and currently very panicky. She said she was ‘very balanced’ for her two older girls. However her one year old son had a neonatal stroke in the postnatal period and her daughter Eve had a near escape in a road accident:

“...I was over analysing everything and over bothered about everything... Unnecessarily waking him up out of sleeps and very fearful of both of them which was never me... I suppose this was my first time being at home with two small babies and being very confined I was very ready to go back to work, and very ready to have a bit of balance. I think I was tipped over the edge, and overly concerned about them and molly-coddling them and checking on them, ... I wasn’t right for a long time after (Eve’s near road accident), and it is not like me because my coping mechanisms are generally quite good, we would have had a lot of things (reference to family tragedy) when I was younger at home, my coping mechanisms are quite good... So the in-toeing and all that would have become more of an issue throughout my pregnancy and after he was born because I was more fearful for her... Possibly had I not been pregnant or breast feeding or had
In contrast to Ella, Felicity’s sense of fear became heightened when her daughter Sarah who already had a growing list of development problems was found to have another problem. First there was a neck problem, then a hearing problem and in addition Sarah had speech and behaviour problems. Felicity’s ‘heightened sense of fear’ provoked concerns about her child having serious developmental problems that prompted her to seek help from a specialist in order to allay the fears associated with her uncertainties regarding her child’s development:

“...when Maura (Physiotherapist) started wondering about her hips I started freaking out then you know oh my God like ... is there going to be something developmental and like it was then that we decided ourselves to go to Professor X you know so like Maura didn’t even suggest going to Professor X but I said I would feel happier” [Felicity 148-159]

Gina’s and Ella’s accounts above show how one’s usual disposition can be altered by not only the problem itself but by what is going on in one’s life at the time. Parents were reflective about their usual disposition and it is clear from the narratives that it is an important influence in any decisions about taking action to seek further help for specific child growth or development concerns.

**Seeking affirmation from family**

Some parents (Edwina, Gina, Noelle, Muriel) described talking to those nearest to them such as partner or family about the concern to seek acknowledgement or affirmation about taking action in terms of seeking the advice of a HCP. Others explained how worries were not equally shared between couples. For example Ella spoke about her partner not being a worrier therefore worrying about Eve falling and the consequences of her other child’s neonatal stroke fell to her:

“…To be truthful about it Peter wouldn’t worry anyway he wouldn’t over analyse anything and he certainly wouldn’t be looking for issues, so no the fact that he is not a worrier I was doing the worrying...” [Ella 388-391]
Sometimes this lack of concern from partners was grounding and helped keep the problem in perspective as described by Ella:

“...he can worry if he needs to (reference to breast biopsy) but I think because he grew up with this and it is a very normal thing in their family he wasn’t worried...He does (keep me grounded) yeah definitely I think if I was married to someone who would have been looking for a perfect child and was worrying about it, I probably wouldn’t be safe to answer” [Ella 393-398]

At other times, lack of partner involvement was frustrating and Felicity spoke about her partner and how she ended up carrying the concern alone albeit with some support from her family:

“...he was (concerned) but you know no offence to men but you know I suppose they are out at work every day they are not doing the hands on stuff you know so he just kind of whatever I said... I get frustrated you know and I would be saying ‘do you not want to get involved in all of this?’, but then on the other hand I know that I like to be in control too you know what I mean? So I wouldn’t have had him doing appointments without me anyway you know and it wouldn’t have changed anything anyway...” [Felicity 244-259].

Parents did not always receive affirmation from their partners and were told the child ‘was fine’ and their ‘relaxed’ attitude was noted to be their partner’s normal temperament or disposition (Sonya, Kim, Ella):

“...George (partner) is very relaxed. He just says ‘he is fine’, he doesn’t really worry too much (laughs)/” [Sonya 198-200]

These accounts show or hint at a desire for affirmation and support which mothers described was not forthcoming. Siobhán spoke about her child Amy’s problem with scratching other children and while Siobhán wanted to get help her husband Scott said Amy should be given more time to ‘grow out of it’ [Siobhan 422]. The couple who struggled most were Antony and Donna because Donna felt Antony did not want to know or listen to her concerns:

“I was telling everything to Antony but he was like you know oh no, don’t worry” [Donna 322]

“So she (Donna) has more experience than I have. So she actually pushed me and we made up our own minds to go to Psychologist privately...” [Antony 63-64]
“He didn’t want to believe it, he was even angry with me… I was asking maybe we go to Psychologist, maybe we go and Antony was saying ah stop you know, this fella (some child he heard about) was five when he started to talk and all that” [Donna 352-353]

This lack of affirmation was very upsetting for Donna because she felt she was carrying the burden of concern and even thought she was ‘crazy’ or ‘imagining’ the concern. Lack of affirmation was complicated by the fact that all their family lived in another country. When they did talk about their concerns to their family by phone or email they felt their concerns were not being heard and validated. Another couple who had no family in the country relied on their faith and religion for support but it did not necessarily trigger action to get help:

“No there is nothing I would have done differently because like we rely mentally on prayer, we pray every day and night… For us we do everything together, we thank God and pray to him. When he got the x-ray that night we pray to God. We don’t have family here …so I cannot talk to anybody so we talk to God he knows everything… we talk to God and pray for him, we don’t talk to anybody” [Jack 238-242]

There were further negative experiences of family not being affirming. For example Gina had to contend with the humorous responses of her family’s attempts at minimising Emily’s speech problem:

“…they think it is very funny like you know that she would say Aunty Tarol and Carol would say do you hear her they think it is really babyish like and I just laugh away and say it’s not Tarol it is Carol…” [Gina 261-264]

So even though the family were trying to minimise the speech articulation problem there was a sense that Gina did not really see the funny side of it. She especially did not want anyone in the family laughing at her daughter and the fact that she would be going to school soon was an added trigger to action. Maternal mothers actively affirmed the concern such as Muriel’s mother who had come to visit: “but that day she was like I see what you have to put up with sometimes” [Muriel 511-512].
Mothers and to a lesser extent, mothers-in-law were both a great source of advice in relation to action to be taken by Gina, Muriel and Noelle:

“...my Mom would be the same as me, always get it checked out you know so don’t second guess it, get it checked out” [Noelle 223-224]

This is evidence of positive affirmation that Noelle’s concern is legitimate. When parents were available, and Siobhán specifically commented on the absence of her deceased mother, their experience was invaluable in terms of understanding normal development and when to wait:

“my Dad and Mom are saying to me he is too young, he is a boy, he is not taking it in you are trying to discuss things with him the whole time and it is all going over his head, leave him, just leave him” [Muriel 268-271]

Ironically, the first person who affirmed Pattie’s concern about her daughter’s lower limb problem was a friend who worked in a shoe shop. However Pattie’s mother was the most supportive person, because of her intimate knowledge of the family history of DDH which had affected Pattie as a child:

“...I definitely would have said to her (mother) ‘do you think I am being paranoid here?’ and she was ‘no there is something alright that she needs to have checked you know’” [Pattie 361-363]

As can be seen from Pattie’s comment, even when she was triggered into action, her uncertainties about whether or not to be concerned about her child’s development prevailed. Child-minders, even though they may be outside the family, they are intimately connected with families. Consequently their opinions were valued and respected. Sometimes they were the first to voice the concern that triggered the action (Siobhán), or affirm the concern (Felicity). In another case the child-minder affirmed Denise’s lack of concern about her daughter’s lack of growth when the PHN was suggesting she needed to be referred.
Seeing the child’s vulnerability

The emergent themes which formed ‘Seeing the child’s vulnerability’ included ‘Impact on the Child’ and ‘Others Noticing the Problem’.

Impact on the child

The growth and development problems causing concern had an impact on the children; some more than others, and these experiences were described by most parents. Kim described how Alan’s speech delay meant it was difficult for him to be understood in the home and even his older brother had to translate for him. It was almost perceived as endearing that lack of speech had made him so self-sufficient:

“He is gas. He won’t even look for something he goes over to the fridge and opens it up and takes out the milk himself or he will pull up the chair for a glass of water...” [Kim 383-385]

Kim acknowledged however that this also resulted in Alan being vulnerable and even his younger sister took advantage of him:

“…He just gets bullied... she (Alan’s sister) is terrible for pushing him and everything and he doesn’t retaliate” [Kim 291-293]

The potential for the problem to impact on the child was described by Muriel in relation in Darren’s eye problem. This evoked fear about harm that needed action:

“...I just felt it (Darren’s eye) was turning slightly and I was afraid the other one might be over working or something” [Muriel 67-68]

No parent however indicated that impact on the child alone triggered action to seek help. Siobhán saw her little girl Eve falling a lot, but as long as she was not crying then the impact was not perceived as severe:

“She actually doesn’t mind like, she doesn’t cry when she falls she just gets up again and saunters on like” [Siobhán 550]

Ella used humour to minimise the issue but the use of nearly laughing is quite telling:

“So yeah and then it got to the stage you would be nearly laughing at her she was so clumsy ...It is (very distressing)...even though you will sometimes take the funny side of it and say oh God will she ever stop, but initially I mean she was
hurting herself for quite a while you know...You will still see it in her and she has boots, little welly boots and when you see her walking in them (laughs) she is like Dinny in Glenroe24” [Ella 322-331].

It was not just the physical impact on the child but also the emotional impact. Muriel in particular spoke about Darren becoming upset and frustrated with behavioural issues and even ending up “balling (crying) in the car” before going into a sports event. Some parents said that because one or other of their children was particularly vulnerable or sensitive they would require extra protection like Alan who was “By nature he is a lot gentler a lot more sensitive...” [Kim 156] and Darren who “...just is that little bit softer ...” [Muriel 870]. Parents described the pre-school years as an important time for identifying schools and preparing their children for school. They were keen that their children were ready for school and in Pattie’s case if her daughter was going to need treatment for her hip then she would just delay her starting school for another year. Part of this worry for Pattie related back to memories of her brother and the teasing he received in school about his feet problem:

“...you remember everybody laughing at your brother and telling you his shoes are on the wrong feet and having to tell everyone well they're meant to be you know” [Pattie 365-370]

Gina too was well aware of what can happen in schools and she was trying to protect her daughter from being bullied so she didn’t want, “...her to be going in with baby talk” [Gina 102].

**Others noticing the problem**

Some problems were very obviously physical and became more noticeable to parents first and then to other family members, albeit not necessarily male partners. Sonya described the neck problem experienced by her son Aidan which appeared at about eight weeks:

---

24 Popular elderly character from a 1980s Irish TV programme that walked with a unique ambling gait.
“So it was really noticeable… My parents were here visiting us and that was around one month they didn’t notice anything because I asked them ... My Mom was back again now last week and she could see it then... ” [Sonya 70-78]

Gender also played a part in assessing the impact of a problem becoming more noticeable to others as described by Felicity in relation to Sarah:

“But actually like one side of her face was very flat she had that thing (plagiocephaly) ...I always felt I suppose you worry about your little girls appearance do you know what I mean?... And like I felt, oh my God when she is older if you tie up her hair is she going to look slightly lopsided ...” [Felicity 132-139]

There came a point where the problem became more noticeable to other people, mostly family. Some of these people were quite direct in calling attention to the problem and others were not. Some parents very clearly remembered the response of other people. For example Felicity said:

“I remember people used to come in and say oh my God look at her head, and I used to be going ‘yeah’ you know and not really making a bit issue of it” [Felicity 275-280]

She reflected that “I was just ignoring it or something you know, not on purpose, not able to face up to it maybe” [Felicity185-186]. Approaches such as this did not always trigger action even when sometimes they could be quite direct. Muriel recalled her sister’s response when Darren was crying excessively:

“I can remember my sister saying to me one time (at her home) you really should bring him up to A & E there is something wrong with him, and I was saying there is nothing wrong with him...” [Muriel 202-204]

Yet there were others who clearly did notice the problem but chose not to verbalise it to the parents until after the referral had been made:

“Then a lot of people said to me ‘oh we did notice that it was very bad’... everybody said it then like” [Felicity 176-181].

Connie in particular reflected in depth on the directness of other people. In relation to family, friends and acquaintances she held the following opinion:

“You see people don’t want to insult you necessarily, I mean my husband would kind of go ‘yeah definitely Colm and Conor were probably speaking sooner at this
(Nigel’s) age’, my child-minder didn’t want to say anything to upset me, ...So my sister probably would have been a bit you know she would be polite and go yeah but not saying there is something wrong with your child, but again you know it is different experiences...our sister-in-law lives in (Place name) and she was down one time and she is my nephew’s Godmother and she says to my sister about his eye, and my sister said ‘excuse me!’ And she said his eye is turning in, and my sister hadn’t noticed anything and was saying to me ‘do you think there is something wrong with his eye?’ and I was like no, and we were like ‘isn’t that a terrible thing to say to somebody. Even if you thought it would you say it directly?’ My sister-in-law wasn’t being unkind she was being concerned you know...You know like a friend of mine said to me before I told her my second child had autism. When I told her she said ‘I knew, I just knew from the way he was standing and he was rocking as he was speaking’. Now she has a child in the autism spectrum so she is ‘in the know’ but again wouldn’t say it to me until I initiated the conversation first but that is the way people work you know... So it is a big deal to people which I understand” [Connie 111-135]

Even though Connie understood why people were reticent about being direct about an obvious problem she had different expectations of professionals who were providing a service:

“...but the problem is I think people need to be a bit more direct about things and that is why...when they (in the playschool) were saying to us you know I think you need to bring him to see somebody they should have said to us he needs to be assessed for autism as hard as that is to hear...” [Connie 340-344].

In Connie’s case she clearly expressed that she needed other people to be direct with her and draw her attention to the problem with her child and thus trigger action to seek professional help. In contrast Donna described a point where she was driving and her daughter had been commenting about Oscar ‘losing his words’. Donna said:

“We are busy we sometimes don’t notice things and then I think children are very good to show you something...” [Donna 365-369]. Donna’s older daughter was 11 and was just stating what she observed but it captured her mother’s attention in the midst of all the other things demanding her attention.

Perhaps the number of people noticing it may have been a trigger factor as stated by Kim:
“...because even coming up to the two years there was no interest, and a lot of people even mentioned it do you know he is very quiet. Is he talking at all?” [Kim 91-92]

Similarly Siobhán spoke about her mother-in-law and her child-minder saying separately to her that Amy was falling a lot:

“…I didn’t even notice it she (child-minder) said ’Siobhán did you ever notice her balance, have you any concerns about balance’ and I was like no, she was going ’Siobhán she is falling an awful lot’” [Siobhán 383-385]

Siobhán said that she was ‘very grateful for people being honest’ which was in contrast with her sister who she said would be ‘biting her lip’ before she would say anything about Amy’s behaviour. Pattie also said: “So I suppose when others started to notice it then I was going yeah OK ...” [Pattie 54-55]. Ella heard her sister-in-law say to her ‘gosh its (Eve’s in-toeing and falling) noticeable alright’ and summed up very aptly a parental desire for perfection: “You don’t want them different at all, you don’t. They come in a box you want them to stay in the box” [Ella 765-766]. So perhaps when more people point out problems directly, parents eventually in time face up to what is noticeable to others and are triggered to act.

**Time passing**

For some parents when they first felt there was something wrong with their child they acted on it after a period of time by going to their PHN or GP who then referred the child to second tier services. Sonya was quite matter of fact in her assessment of this time:

“...it is basically a month ago I think. So it was probably around when I started noticing it and I just went and mentioned it... (Laughs) so yeah it was just probably a week after or something like that” [Sonya 107-113]

Muriel described her experience of a slightly longer period of time before taking action and going to the PHN:

“I would say it was probably the bones of two months. I would say I was probably not paying much attention for a month and then the second month I said there
could be something I better go see about it ...So I really probably ignored her a little bit and I kind of don’t run off with them the minute do you know what I mean, I like to judge a situation so when it wasn’t easing I said it is better to be safe than sorry I will just get it checked out” [Muriel 86-97]

This implies an almost structured ‘wait and see’ approach to consider the problem in the context of time passing. Noelle similarly treated the concern in a non-urgent way:

“Well I would have raised it to Sean (partner) immediately I suppose just to see was it the way I was looking at her or not but I didn’t actually raise it to Mona (PHN) I would say for maybe about a month because Mona was coming to us with our youngest ... so I just kind of left it for her next visit as such” [Noelle 49-53]

Going to pre-school or primary school was perceived by some parents (Felicity, Pattie, Gina, and Kim) as a looming deadline for action:

“I noticed the same pattern with Sarah and I said we will have to get this checked before she goes into preschool/playschool ... in January” [Felicity 398-400]

Parents spoke a lot about time passing but it was not unusual for parents to have difficulty recollecting dates and they were not always very clear or precise about time periods.

Parents also reflected on time passing while waiting for initial assessment and the results of the referral appointment. In particular Antony and Donna reflected in depth on the ‘battle with’ and impact of time passing:

“...she (GP) told us to wait half a year basically. And she said to us when will he be three (years old)...just go to psychologist privately...Yeah so we were waiting and we were losing time and Oscar was getting worse actually” [Antony 45-52]

They spoke about being “really sad that we lost so much time” [Antony 821]. In complete contrast to Antony and Donna, Connie was waiting six months to be seen from the initial referral but seemed unfazed by this delay:

“If I was a first time parent or I was a person who would panic I think I would probably have lost the plot altogether awaiting for six months but actually I think it ended up taking about six months. It was a few months anyway but it seemed to come around quite quickly again because I wasn’t overly anxious about the situation, but that’s me” [Connie 32-39]
Although autism was the common condition in both families it would appear that Oscar’s need for intervention was greater than Nigel’s, who was considered by his mother Connie to be high functioning. Additionally Connie, as discussed, earlier perceived herself as a non-panicker so both usual disposition and long waiting times accounted for delayed action with her son.

A number of parents expressed guilt about not seeing the problem sooner or when they did not acting with enough urgency. Siobhán said she might have gone for help sooner. Some parents described various family stresses that would have affected both their ability to concentrate on assessing a concern and then on managing a concern with their child. Noelle also had some delay and admitted “there would be a little bit of guilt” but did not have regrets:

“…I would say I probably would have raised it quicker but I mean it is not something I am struggling with because she doesn’t have a problem with it, maybe now if the referral had raised an issue I would say why didn’t we say it sooner. But the fact it hasn’t raised an issue I am quite happy with everything” [Noelle 93-97]

In Noelle’s case there were stresses in the family with the birth of a younger child with Downs Syndrome who also had cardiac complications. This required surgery and it may have been the case that Olive’s legs were of secondary concern. In Kim’s case she was running a business from home and her little boy Alan was very ‘easy’ making it difficult to notice his speech delay until things quietened down at work:

“…they are all so different, Tiernan was a little bit more needy I suppose being the first child you give all your attention to him, whereas when Alan came along Tiernan was still demanding that attention and sure he wasn’t able to say nothing to you, you just popped him in the corner and he was an easy child anyway, or the telly gets turned on a lot more than what it should as you can see it is on there now trying to do 101 things” [Kim 362-370]

Kim also described a health problem that had been bothering her for at least six months. Although she did not say it explicitly this spanned the time Alan’s speech
problem was becoming more obvious and it was other people who had triggered the referral by calling attention to his speech delay. When triggers for action aligned for parents, moving to the next phase of expressing the child growth or development concern to a HCP was inevitable.

Getting child’s problem checked out

This super-ordinate theme ‘Getting child’s problem checked out’ contained three subordinate themes. The first subordinate theme is called ‘Just Check it Out’ and refers to the process of going for help and how parents went about expressing their concern to a HCP. The second subordinate theme is called ‘Getting into the Health System - Public or Private’ and refers to who they considered the most appropriate HCP either before they went or reflecting in hindsight. The final subordinate theme is: ‘In the Hands of the Professionals’ and refers to HCP validation and therapeutic relationships in relation to the parental concern (see appendix 15).

Just check it out

This theme originated from two emergent themes which were ‘Better Safe than Sorry’ and ‘Concern Mentioned in Passing’.

Better safe than sorry

For some parents going for help was a straightforward matter of asking to be seen or just going to a health centre or surgery. Many parents were already attending for regular health check-ups as part of preventative child health services (Denise, Muriel, Gina, Edwina, Sonya, Jack). For example, Sonya was a regular attender at the well-baby clinic run by the PHN: “So I just asked her because we go there and we just weigh him every second week” [Sonya 22-23]. Edwina just went to her local health
centre about her son’s speech problem: “… I went to health centre in (place name) and asked” [Edwina 67].

Even parents such as Denise and Meg who did not express a concern to their PHN still felt it was safer to ‘go along with’ having the problem checked out when an appointment was made for them indicating a more passive approach:

“Obviously you do want to go and get it checked but it wasn't something that I thought was an issue. So obviously when you are referred on: / I obviously went along with it” [Denise 27-29].

Meg also ‘went along’ with the referral even though there was no visible problem:

“Well when they asked me at the check-up if there was any family history I myself had a squint, so they said there wasn't any stronger link, so they said for that reason they said they would check it out” [Meg 8-11]

It was clear from these two accounts that even though they did not approach a HCP initially to express a concern there must still have been a niggling uncertainty that was safer to have checked out.

Parents who had a concern, albeit not severe, like Muriel’s concern about Tricia’s ‘fuzzy eyes’ also felt the need to err on the side of caution and just get things checked out:

“I like to judge a situation so when it wasn’t easing I said it is better to be safe than sorry I will just get it checked out… He (partner) said we’re probably better off getting it checked out, he felt she was just getting tired as well” [Muriel 96-102]

Noelle reflected that getting things checked out promptly when uncertain was the norm in her family:

“It is as simple as that…and my sister would be the same. We would parent on the lines if we are not sure we get it checked we are not the type that if we’re not sure we are waiting to see how it goes out…and I know I have friends that would be like that, that probably think we could be a bit neurotic at times because we get everything checked out” [Noelle 230-232].
Overall this emergent theme: ‘Better safe than sorry’, was characterised by a matter of fact, or sureness of behaviour from parents in terms of how they acted which contrasts with the following theme.

**Concern mentioned in passing**

In this theme, parents (Gina, Muriel, Ella, Noelle, Pattie, Kim) descriptions were very tentative as if they were unsure or uncertain about how to express the child growth or development concern. Gina described how she took Emily for her developmental check with the intention of bringing up the speech problem:

“...it was actually her check-up before she goes into preschool. So when I brought her I just mentioned to Tina (PHN) that she mixes up like “T” and “C” instead of saying coke she says toke, instead of saying frog she says “srog”...”

[Gina 9-12]

Gina’s reference to ‘just mentioned’ above is striking in that she raised the concern within the context of an overall check-up. It did not seem to be her intention to dominate the health check-up with her child’s speech problem but rather to ‘mention it in passing’. Parents such as Muriel and Ella had the concern on their agenda or on a list of questions to ask when they next had a visit with a HCP. Noelle took this approach with her GP:

“I raised it in passing... We were going (to the GP) about something else, I think she was unwell at the time when we brought her and I said while we are here will you look at her knees kind of thing” [Noelle 80-84]

However Noelle stated that “the G.P. said it looks fine” [Noelle 274] which did not validate her concern. She raised the concern about her daughter’s knees again with her PHN during a home visit by saying she was ‘a little bit not sure’ at a later date. Pattie was also tentative in her approach to the PHN using the phrase ‘happened to say’:

“I felt she was assessed very fast, she (private physiotherapist) put her on orthotics and then I still wasn’t that happy. I happened to say it to my public
health nurse I said do you know I was a little bit concerned and straight away she acted on it” [Pattie 11-14]

It is obvious from this account that Pattie was not satisfied about how the private physiotherapist was managing her daughter’s lower limb problem and Pattie’s concerns persisted.

Ella, using a very interesting turn of phrase ‘didn’t bring her anywhere’ succeeded in separating universal or primary health care from second tier services:

“So I didn’t bring her anywhere I just happened to mention it to the Public Health Nurse and she said she would refer her on” [Ella 59-61].

A number of parents (Muriel, Ella, Gina, Sonya) used the word mention or mentioned capturing the informality of the well-baby drop-in clinics run by PHNs where any child care issue is open for discussion. Whereas Noelle used the phrase ‘brought it up with the GP’ possibly implying a more formal consultation, a few parents (Noelle, Kim and Muriel) expressed explicitly that their concern was ‘not enough’ to go especially to the GP:

“I raised it on the day but it wasn’t enough for me to go to my GP or anything like that. It was on my list of questions for Brenda (PHN) and Brenda picked it up actually straight away” [Kim 240 -244]

Muriel admitted that not going to the GP was for financial reasons and admitted it sounded ‘awful’:

“I don’t think I would have you know because I would have said if it is a case going to your GP and this sounds awful, you go to your GP and it costs €50.00 that sounds horrendous but if you have a child that is just walking on her tippy toes every now and again I am not going to bring her to the doctor for that so you end up not asking anyone so really I have found the District Nurse (PHN) fantastic just to run something by because she is looking at so many other children” [Muriel 658-666]
This account suggests that a parent associates a GP visit with managing a child’s acute illness and not with child development problems, whereas Muriel just wanted advice, ‘to run something by’ the PHN before making a decision to proceed further.

**Getting into the health system, public or private**

Once a parent decided they needed to seek assistance from a HCP a number of factors relating to services had a marked influence on them. Their decision about which HCP they would go to was determined usually by their knowledge of what service to use, their past experience of, or preference for either public or private. Sometimes they had an existing professional relationship with a PHN or GP that influenced who they approached first for help.

Parents sometimes made obvious choices about what health services to access to express their concerns. This tended to happen for those parents who initially went privately to their GP and continued privately thereafter. Antony and Donna realised that because of their lack of knowledge of autism and health services they ended up trying to access and coordinate private services such as psychology, S&LTs, OTs, private tutors and nutritional support for Oscar to ensure he received intervention early. As a result of this they formed strong opinions about private health practitioners who could charge “…€600.00 (laughs) for two hours work” [Antony 190]. In Donna’s view the whole private system was ‘crazy’:

“So come and pay and I will see (laughs)... when your child is sick or have any conditions because this is horrible [sic], but there is lots of people who want to make money on it you know and parents are desperate, like we were desperate, we would pay anything, as much as we have, we would do everything” [Donna 513-517]

Antony, Donna and Connie also spoke about private preschool services, in that they expected them to have more knowledge of autism and be proactive in advising
parents how to go about seeking relevant services. This highlighted a knowledge
deficit in parents about where to go for help. In hindsight Pattie said she too should
just have made other choices:

“Probably skipped the physio (laughs) in (place-name) because I just think she is
probably more for sports injuries and things and I just probably should have
bypassed all that but at the time I thought orthotics, or else gone straight to Foot
Solutions25 they are brilliant ...The girl up there even said to me this is coming
from her hip but she said I can’t check that for you...” [Pattie 229-240]

Parents who started in the public system with GPs or PHNs tended to have more
positive experiences even though they may have been described as slow and
bureaucratic at times. In particular the parents of children with autism: Connie,
Antony and Donna had very strong opinions of public services. Connie understood
about the lack of resources in the public health services and the possibility there were
more pressing cases in the deprived area near where she lived. She also admitted that
her experiences were probably coloured by the personnel she previously met. While
stating that she would not in hindsight change her action, she said she at least had
choices which were accessing private services if necessary:

“The impression I got was that you know they are over worked, under resourced
and they couldn’t cope with the people coming in but I think they somehow need
to balance that with encouraging people to approach them with concerns...
Honestly that is why I say the 3.25 year check-up26, now if I don’t get called for
that, there is no way I am calling up to that Health Centre...” [Connie 556-581]

However, Connie admitted that once she got access by referrals to various services
such as S&LT and physiotherapy, services were good: “so once I got in the system it
was very good...” [Connie 43]. Connie was eager to acknowledge that her experience
differed from other parents:

“...I know other mothers with children and you know you hear some wonderful
reports of the public health care system and then my experience hasn’t been great

25 Foot Solutions are a commercial enterprise staffed with experts trained in foot and gait
biomechanics
26 The last formal developmental assessment before school entry takes place when the child is aged
between three and a quarter and three and a half years.
all and all …I wasn’t called for assessments you know. There is a bit of ‘drop into us anytime’ and I did ‘drop in’, and I felt it wasn’t well received, I felt it was a bit of an inconvenience, so if you have a doubt or a concern it needs to be a fairly big concern to really be pushing through all of that inconvenience.” [Connie 181-191]

The most telling point was that the service as described was not conducive or convenient to Connie expressing concerns about her child’s development. She believed that because of her history she should have been prioritised: “...there is so much evidence that it (autism) runs in families...” [Connie 441]

Antony and Donna mirrored the type of parents described by Connie. They were foreign nationals who went to a GP who equally knew nothing of Irish public health services. After accessing a variety of private services they could ill afford, they finally got a diagnosis of autism and started accessing the public services. Here they met what they described as a ‘bureaucratic nightmare’ as they battled to put services in place for themselves and their son. They had considered going back to Eastern Europe but from what they had discovered the services were better on balance, in Ireland. However, the delay in setting up HSE early intervention services was frustrating for them: “...to wait those eight weeks even for such a simple report...” [Antony 158].

Felicity had more mixed albeit mainly positive experiences with her daughter Sarah who attended services initially in relation to a concern about torticollis and plagiocephaly which were followed by hearing and speech difficulties. She had considered going privately initially but a public appointment ‘came through’. She spoke very highly of an ‘expert’ paediatrician’s input as well as the input from primary care services, including public health doctors, dentists, PHNs and others in

151
the health centre. She acknowledged how little the service meant to her before she had real need for it. Felicity described the fact that made the service provided by the public health doctor and nurse great was the fact that she felt unrushed and listened to when she expressed her concerns:

“But she kind of you know made it easier for us you know what I mean, I have never felt rushed I suppose I have been able to sit and talk about the whole hearing thing that Sarah had …It definitely seemed to work…” [Felicity 674-688].

The telling thing from the above narratives and aptly described by Felicity is that parents do not really appraise the worth of a service until after they have need to use it. It is only when they need it again that they are drawn back to that which was found to be responsive or where a relationship with a HCP was already established.

**In the hands of the professionals**

Parents spoke of being ‘In the Hands of the Professionals’ a theme that emerged from ‘Professional validation’ and ‘Therapeutic relationships’. These emergent themes were critical to how parents felt their concerns were managed by HCPs.

*Professional validation*

The manner in which a HCP acted on the parental concern to make a referral was seen as a form of acceptance of the concern or a professional validation:

“I happened to say it to my public health nurse I said do you know I was a little bit concerned and straight away she acted on it”(made a referral) [Pattie 11-14].

However parents needed more than just unquestioning acceptance of the parental concern as articulated by Ella:

“I suppose I would have felt the Public Health Nurse that I spoke to that day I won’t say I felt she was dismissive she certainly wasn’t concerned about anything and she didn’t address it she just did out a referral…I said that I felt she had a squint she didn’t look at that and the in-toeing she tried to look at her walking across and she said I will just do a referral so she didn’t over analyse it or under-analyse it I would say [Ella 413-421].
Parents spoke of putting a lot of thought into appraising the problem and when parents expressed a concern the last thing they needed was to feel that they were imagining it:

“...I was actually kind of relieved you know that somebody (PHN) was actually saying OK we can do something you know what I mean that she is not just going to grow out of it lets actually do something about this...” [Felicity 326-329]

Felicity acknowledged that it is normal for a HCP to try and reassure a parent when they express concerns about their child. However, on reflection because of her GP’s initial reassurance she had ‘let it lie’ for a quite a while, almost ignoring it. She recalled how her inaction because of inappropriate reassurance had really upset her. Unsurprisingly, parents who were trying to appraise more subtle problems seemed to have more difficulties convincing HCPs of their concerns. However, it was also the case that when a concern was addressed by professionals and followed by very positive reassurance doubts remained in some parents minds:

“I would have to say I am 90% reassured there is always that thing that I am still looking at her knees and they still have that physical look. So I suppose no matter how much people say it is fine I was still looking...” [Noelle 166-169]

Nevertheless the opinion of specialist HCPs that children had been referred on was seen as the main factor that could reduce parental concern. Some parents had been seen by specialists and others were still waiting so they did not know ‘what they are going to say’ [Sonya 309-310] but like Siobhán were going to leave ‘it in the hands’ of the specialists. Gina had unanswered questions about her youngest daughter’s speech problem and wondered if it could be related to dyslexia. Her older daughter had the same speech pattern and had difficulties in school before dyslexia was finally diagnosed. She was very concerned that her youngest would not fall through the net so she was determined to go for the appointment and get an expert opinion:

“…and just see what they say...hopefully when the referral will come it might be after correcting itself but I will still bring her” [Gina 558-560].
Once Gina had taken the step of expressing her concern to a HCP and obtaining the referral there was a commitment to seeing it through to the end analogous with closing a loop. However there was also tacit acknowledgement of the dynamic nature of child development and that parents could be taking this route again either with the child of concern or his/her sibling.

**Therapeutic relationships**

Parents who had good experiences and established therapeutic relationships with HCPs frequently referred to them by name in their narratives. The majority of relationships experienced by parents related to GPs and PHNs which is unsurprising given that these two professional groups serve as the first point of contact with primary care services. Some parents did not have good experiences with GPs in seeking their advice about their concerns. Antony and Donna in particular spoke a lot about this and to some extent it dominated their experiences of getting help for Oscar. Oscar was two at that time and his speech was regressing along with other symptoms. Their GP told them to wait for at least half a year before worrying and then go privately to a psychologist, if necessary. They heard afterwards how incorrect this course of action was. They and others were very upset and felt angry or ‘let down’ (Sonya, Felicity, and Ella) about their experience of voicing their concerns to their GP. Antony and Donna even experienced disinterest from their GP:

“…it really hurt my feelings she said to me that she didn’t know anything about autism and if it was her child she would know all of this and we knew at that time. She wasn’t really interested because her children are perfect” [Antony 762-766].

Therapeutic relationships with the PHN were found to range from relatively non-existent (Connie) to being considered part of the family (Siobhán). Connie described in detail her feelings about PHNs which were largely coloured by her own past experiences. She felt the PHN who visited her home eleven years previously was not
very professional in her demeanour. She reflected on very different experiences even within her own family:

“...I have a sister-in-law who lives in (place-name) and she was practically best friends with her public health nurse, calling her up for advice, and had a really good relationship with her...I had no relationship, now I didn’t want a relationship necessarily, but I think if I had wanted one, it wasn’t there for me do you know what I mean?...So I found the public health nurse system in my experience, they came to your house when you had a new born baby, they kind of made sure that the child was in a safe environment, they maybe came back another time to weight the child and that was it. ...I felt then I was out of the system after that, I didn’t need a support system but if that was the purpose of the Public Health Nurse system to catch early developmental signs I certainly didn’t find that there...I know my sister who lives in (place-name) I think had a probably better experience with the public health care, I think her experiences are probably as it should be...She was called for her check-ups, I think she did drop in maybe just to have the child weighed and that kind of thing but didn’t need an awful lot of support. But I think the support was there had she needed it so I think her experience was probably as it should have been, it wasn’t amazing but it wasn’t under supportive as well...” [Connie 193-221].

Connie also spoke about her non-existent relationship with her GP and indicated that it was because she had very little contact with her. Even when Connie was in contact with the GP she said she did not even remember that she had two older children with autism. In contrast, Denise had a very good relationship with her PHN previously when her daughter was born by caesarean section. However she felt a bit overwhelmed by her during the period surrounding the concern about Cara’s height, which she stressed, originated with the PHN:

“I think I might have argued with the public health nurse more, in the sense that there was no issue but at the same time you are kind of at people's mercy ...I'm glad I took her but in hindsight I don't know would I have been as (words unclear) Nobody else had noticed it that she was small for her age...” [Denise 127-134].

For those parents who had good or excellent relationships with their PHN they considered it was very important that the PHN be a person who was approachable and that they could just ‘run something by’ that is, their concerns. PHNs were variously described as ‘knowledgeable’, ‘brilliant’, ‘fantastic’, ‘sociable’, ‘kind’ and ‘lovely’ with the children. They were also described as ‘sound’, ‘precise’, ‘direct’
and ‘easy to talk to’. Muriel described her experiences with two PHNs who were polar opposites:

“...Well she is very good that girl Inez (PHN), she has a lot of experience and you know you would have no problem picking up the phone (to her). I did have one (PHN) now on Darren and I never would have picked up the phone to her... I just didn’t get a nice warm feeling off of her and I didn’t feel secure in any way ... I never would have picked up the phone (to her) whereas Inez I just find she is just a ticket...” [Muriel 779-800]

It is clear from Muriel’s relationships with two PHNs, she found Inez open to letting her express her concerns which contrasted with her experiences with another PHN.

Muriel appreciated having the freedom of being able to just pick up the phone and ring the PHN if she wanted to. Sometimes the relationship had built up and deepened because of regular previous contact. Evidently having a continuous relationship with an approachable, trusted, knowledgeable professional was conducive to parents expressing their concerns. Noelle described her PHN Mona coming to the house regularly because her youngest son Ciarán had Down’s syndrome with cardiac complications requiring on-going nursing input. This made expressing her concern about Olive relatively convenient:

“…so I just kind of left it for her next visit as such… I think more so I had it in my head to go through Mona rather than the GP I don’t know why” [Noelle 50-53].

Parents were probed about whether location made a difference in voicing their concerns. Kim said while it was ‘easier at home’ she preferred being able to get out to the clinic. Noelle was asked if she felt more comfortable and relaxed at home or in the clinic setting and her reflection was very illuminating:

“... I felt because Mona was visiting at home with Cian I was actually comfortable to talk about Amy and Olive... I just said do you know Mona ‘I am a little bit not sure on this’ and that is where it came from. So that is the one thing I would say I definitely think the home visits are at that age a lot more use...But definitely I think a clinic environment you are conscious that there is other people waiting in the waiting room and you just go in and get that check done and out the
Therefore while location is a consideration from the point of view of parents being at ease in their own surroundings it is possibly more to do with parents feeling unrushed and feeling they have undivided attention of the PHN to listen and hear what they have to say.

Summary

These findings represented the interpreted experiences of a sample of typical parents of preschool children with a range of child growth and developmental concerns. Mothers rather than fathers were either aware of problems with their child from birth or they become aware of it by noticing it later. They described the concern ‘as it is’, in lay terms that were clear to them. These descriptions were vivid and sometimes lengthy. On occasion while the first growth or development problem was being appraised a new concern appeared that seemed unrelated to the first. Child growth and development concerns were also articulated about other children in the family. Concerns impacted on the family causing stress and daily challenges. The referral was usually a clear process in that a referral was made to a HCP, an appointment scheduled and period of waiting occurred.

Mothers usually spent time watching the problem for a while before they spoke with family. Many made comparisons between their child and other children. Some were particularly uncomfortable with comparing their children with others especially outside the home. They assessed other aspects of the child’s development to reassure themselves that the child at least was ‘doing other things’. They watched and puzzled...
about the problem, wondering, looking for a cause. Ultimately they formulated an opinion that they were ‘a little bit not sure’ or uncertain about it.

Parents were influenced in their assessment and sense making of the child growth and development problem by their experiential knowledge, or ‘being in the know’ and where they went informally to seek information such as internet or TV. The triggers to do something about the problem came from: parents’ usual disposition to panic or not; other stresses in the family; affirmation sought from family; or specific prompts such as child vulnerability and the impact on the health or well-being; or the problem becoming noticeable to others. Other triggers were time passing, or a looming deadline such as starting school.

Getting the child’s problem checked out was either straightforwardly ‘just check it out’ or tentatively ‘mentioned in passing’. This latter occurred when parents attended routine PHN assessments and had the problem on their agenda or list of questions. Parents made decisions to access familiar or most accessible services, often coloured by their previous experiences. Some had to express the concern to a HCP more than once because it was not heard the first time it was said. Existing therapeutic relationships facilitated expressing a concern. When a child growth or development concern was validated by a HCP parents were happy to defer to professional or specialists opinion. While there may have been a loose linear trajectory evident from noticing a problem leading to the appraisal of a concern, referral and resolution, in reality the influential factors influencing the trajectory along the way often happened concurrently.
Chapter 5: Discussion

In this chapter the results from the previous chapter will be interrogated with the empirical and theoretical literature consistent with a central tenet of IPA, as suggested by Smith et al. (2009). The chapter will commence by discussing the context of parents’ experiences using the two contextual themes ‘The Concern – telling it as it is’ and ‘Referred on’. The remainder of the chapter will be structured around the four superordinate themes identified in the study, namely: ‘Uncertainty – a little bit not sure’; Parental Knowledge – ‘being and getting in the know’; ‘Triggers to action’; and, ‘Getting the child’s problem checked out’. The chapter will close with the limitations, final conclusion, and recommendations for practice, research, education and policy.

Experiences of ‘The Concern – telling it as it is’ and being ‘Referred on’

The type of concerns parents had were varied and related to speech and language, gross motor, skeletal/structural, vision, and growth. As such these children had growth or developmental delay that could have placed them at risk of a diagnosis of a developmental disorders whether specific (SDD) or pervasive (PDD). One child had a confirmed and another child had a probable PDD diagnosis indicating a full range of seriousness in terms of developmental delay/disorder. Parents’ narratives around their children’s problems were often lengthy and highly descriptive. The subordinate theme ‘The Concern ‘telling it as it is’ captured the lay manner in which parents described the focus of their concern. It was unsurprising that parents used these lay terms because they did not have access to or understanding of developmental paediatric language. It could be argued that the rich indicative detail describing the concern was necessary for parents to try and articulate or name the concern so that they could talk about it to others inside the family first and at a later stage to a HCP.
Ryan and Salisbury (2012) similarly suggested that being able to articulate a concern about an early sign of autism was necessary to expressing it to a HCP. Glascoe (2002 p. 88) stated that “parents rarely list complaints in their order of importance” and in fact the most predictive complaint in terms of formulating a diagnosis may be last. There was no evidence that parents tried to list complaints although they may do this in a formal consultation with a medical practitioner when constrained by time. Glascoe (2002) indicated that leaving the most predictive complaint until last can impede effective reasoning for medical personnel as they use anchoring as a diagnostic technique. The technique of “anchoring is the use of an initial hypothesis for evaluating the importance of subsequent observations” (Glascoe 2002 p. 88). This technique is not typically used by nurses but it could account for the fact that GPs particularly, as described by parents, did not always hear or pick-up-on the expressed concern.

The current study found that parents were concerned, sometimes more so, about a child other than the child of concern. Concern about an older or younger child other than the ‘child of concern’ was experienced by seven of the fifteen parents. The type of concerns parents had about these other children ranged from behavioural problems to dyslexia. Parents had not always expressed the concern about this other child to a HCP which they had attributed to inexperience and lack of knowledge about child growth and development. Their realisation that there was a developmental problem was in hindsight provoking a sense of ‘guilt’ and fears that a child ‘fell through the net’. The use of the term ‘net’ draws attention to an expectation that child health preschool and school services should be like a safety net that would catch development problems that first-time parents could miss. The concept of the ‘net’ may also refer to
an acknowledgement by parents of the limitations of their lay knowledge and suggests the need to have a preventative child health service based on expert child development knowledge to support parents. Guilt was expressed by other parents (Kim, Noelle, Felicity) implying they should have picked up the problems sooner or acted on them sooner. However, there was no evidence that the guilt experienced was like the level experienced by mothers in William’s (2007) study who felt that they had somehow failed to be ‘good mothers’ because their child did not have a smooth developmental path. The differences in relation to guilt may be that the signs of developmental problems were more subtle, the journey to diagnosis took longer, and the child suffered more adverse consequences in school.

In the current study two parents expressed their concern to a HCP almost immediately whereas all others delayed from two weeks to a year. This delay supports the findings of previous studies reporting on the time from first suspicion of a concern to expression to a HCP, varying from: one year for speech and mild cognitive delays (Watson et al. 2006); 1.6 years for neuro- motor delay (Ehrmann Feldman et al. 2005); and two to four years for autism (Noterdaeme and Hutzelmeyer-Nickels 2010). In the current study there was a sense that parents delayed seeking help until the problem was clearer or more established; a strategy that is supported in previous research in relation to overweight children (Edmunds 2005) and for PDD where the mean age of first symptom was 18.6 months but the age at referral was 14 months later (Chakrabarti and Fombonne 2005).

Parents in the current study were typical of parents who express child health concerns to HCPs in that they were mostly mothers aged 35-39, social class group
one to five. This mirrors the findings of other studies (Blair and Hall 2006, Magnuson and Hergils 2000). Once parents expressed their concern to a PHN they were referred-on, immediately in most cases following which waiting times for second tier appointments varied. Being referred on was viewed as a process that a parent and child went through together, culminating in ‘waiting for an outcome’. This ‘waiting’ period of uncertainty was found to be a stressful time for parents; a finding that supports previous studies (Baker et al. 2003, Herring et al. 2006, Santacroce 2003). It was also found to be a time where parents appreciated as much HCP feedback as possible and something to work on with the child such as physical exercises or language stimulation. This may be because parents can see results in the child from structured interventions and working on the problem enhances their sense of purpose in the presence of possible continuing uncertainty about the nature of the concern. It is widely acknowledged the speech and language therapy waiting lists are lengthy, care pathways need improvement (Hough 2012, Murphy et al. 2012) and there is much that parents can do to improve their child’s speech and language while waiting (Auert et al. 2012, Hayes et al. 2012). For example, Gina spoke about the whole family getting involved to help her daughter. However, there was a sense that they were trying to help without clear directions contrary to the recommendation that effective speech and language therapy needs to be structured (Hayes et al. 2012).

Uncertainty – ‘a little bit not sure’

Uncertainty – ‘a little bit not sure’ emerged from two main subordinate themes which were ‘appraising the concern’ and ‘wondering about the cause’. Parents, usually mothers, watched for a while to observe activity and behaviour, looking for patterns and they made comparisons with other children. Watching and checking was also found by Kai (1996) as a parental sense-making strategy concerning acute childhood
illness. Comparisons with other children or with clothes size has been found in other studies exploring parents assessment of their children such as growth failure (Reifsnider et al. 2000, Thomlinson 2002), size and growth (Lucas et al. 2007a), and being overweight (Garrett-Wright 2011, Jain et al. 2001, Small et al. 2009). Making comparisons with other children has also been found with child behaviour and ADHD (Brinkman et al. 2009) and child development (Porter and Ispa 2012). This finding has important implications for practice pointing to the need for HCPs to elicit information from parents about the strategies that they use to make comparisons with other children as a way of starting a conversation to probe their concerns.

Parents commented on the other things their children were doing developmentally as a way of reassuring themselves that at least the problem was not serious if their child was ‘doing other things’. However, if a child had difficulty in a number of developmental areas this made parents more unsure or uncertain. This was not found in previous studies and highlights how parents made attempts to grapple with the complexity and multifaceted nature of child growth and development, in their efforts to make sense of what was happening. Mothers puzzled at the unfamiliarity of the cues and wondered if there was something wrong. Some were familiar with watching normal development, by virtue of having older children but it was really challenging to assess if there was abnormal development and something to worry about. Like Connie’s description of the ‘red flag’ in relation to her son’s autistic-like behaviour this very term was also used by a parent in Missiuna et al.’s (2006) study on Developmental Coordination Disorder (DCD) in the context of an otherwise intelligent child falling behind with her school work. A red flag is a common term denoting danger. As explained in Mishel’s (1988) Uncertainty in Illness Theory
(UIT) uncertainty becomes appraised as danger not opportunity. The uncertainty experienced and the manner in which parents appraised the concern equated with trying to find meaning in unfamiliarity of the cues in the presenting problem or stimuli frame as described by Mishel and Clayton (2003) and Penrod (2007). This means that parents try to find meaning in the unfamiliar cues of child growth and development and not just with cues associated with acute illness as in Mishel’s theory.

In the current study ‘wondering about the cause’ took parents’ assessment of the child’s problem to a deeper level and had not been found in previous studies. For example, parents wondered if delayed dentition was related to delayed speech (Kim) or if position in the womb caused neck stiffness (Sonya). These are reasonable appraisals and have some evidence base (Adewumi et al. 2012, Herman 2006) but others like Antony and Donna’s belief in the MMR vaccine causing autism or Muriel’s fears that Darren’s ‘struggle being born’ contributed to behavioural difficulties can add to ‘understanding lay theories about illness causation’ originating in discourses about lay knowledge (Henderson 2010 p. 4). It is natural for parents to look for explanations or something to blame (Bearman 2010).

Wondering about the cause is similar to inference as described by Mishel and Clayton (2003). Inference refers to the assessment of uncertainty using associated examples and builds on knowledge and contextual cues and as such is part of the process of interpretation (Mishel and Clayton 2003). Therefore, Uncertainty in Illness Theory offers some useful insight from an illness perspective that is applicable to child growth and development. Despite Muriel’s belief her husband
thought she ‘was mad’ for thinking that the manner of being born had anything to do with her son Darren’s behaviour. Muriel had not, possibly as a consequence of her husband’s reaction, expressed that uncertainty to anyone else. It is vital for HCPs to listen to parents’ ‘theories’ without dismissing them or minimising their lay knowledge. Some parents in the current study felt their partners dismissed their ‘wondering about the cause’. An open attitude is more likely to facilitate expressing the concern because parents are less likely to worry about feeling silly.

Not all uncertainties were fully voiced by parents to HCPs. It could be that they felt silly for thinking it like Muriel, or perhaps it was too frightening to say it. Schick Makaroff’s (2013) concept analysis of the unsayable has potential utility in understanding parents not saying the word ‘autism’ or Ella not saying she feared her daughter had Motor Neuron Disease, despite these fears being alluded to during interviews. The concept of the unsayable is well recognised in psychology and its antecedents may include factors that make something unsayable because it cannot be defined or articulated, or the topic may be too sensitive, undesirable or painful. According to Schick Makaroff (2013), while psychologists focus on analysis of the unsayable it is more appropriate for nurses to be present for patients during illness and suffering and bear witness and thus “support them during these times of uncertainty” (p. 8). In the context of child health and development, nurses need to ensure that they are not dismissive of parents’ fears as they may facilitate understanding and teasing out the uncertainty about the child’s growth and development.
The emotions experienced by parents arising out of their uncertainty varied from being unsure, relatively unconcerned to being ‘scared’. This reflects Penrod’s (2007) assessment of the extent of discomfort associated with uncertainty which “ranges from immobilising fear to a more covered-over, acceptable doubt” (p.662). However, the emotions experienced by parents in the current study varied over time, even with the same child and the same problem. The variation depended on what was happening with the child in terms of whether the referral was awaited or if the source of the concern had been ascertained. Prior to this study, little was known about the emotional impact of uncertainty regarding parents’ concerns about their child’s growth and development. Evidence specific to childhood illness (Dodgson et al. 2000) found that the more intermittent, or unpredictable, the symptoms the greater the impact on family distress. It may have been assumed that child growth and development concerns are less concerning than acute childhood illness and the current findings do not support such conjecture.

Even though the experiences of two fathers were captured in this study the origin of uncertainty about the growth and development of the children came from mothers. They were the first to notice ‘something’; a finding that supports previous studies which have found differences between genders in relation to uncertainty albeit regarding children who were ill (Hoff et al. 2005) or hospitalised (Graves and Ware 1990) or had hearing delay (Magnuson and Hergils 2000). Some previous studies however did relate to parental gender differences in the context of developmental delay (Ahern 2000, Cepanec et al. 2012, Ehrmann Feldman et al. 2005). These studies found that mothers were more knowledgeable of child development and recognising when there was something wrong. Findings from the current study in
relation to gender differences must be viewed with caution as there were only two fathers interviewed. Denial was noted in the context of Antony’s initial rejection of a problem with his son Oscar; a finding that supports previous studies in relation to fathers (Ahern 2000, De Giacomo and Fombonne 1998). However, more research is needed to understand fathers’ experiences of child growth and development concern.

Parents’ experiences were ultimately described as uncertain or a ‘little bit not sure’ which is a different term to parental concern. While there is some evidence from the literature (Kiing et al. 2012) of a possibility of a lack of a common understanding of the term concern this had more to do with language and culture. Whereas, purely in semantic terms ‘concern’ implies one has arrived at an appraisal, whereas being uncertain indicates a preceding or antecedent term. The finding ‘Uncertainty – a little bit not sure’ is similar to a certain extent with the theme ‘unravelling the mystery’ found by Missiuna et al. (2006) with older children diagnosed with DCD.

The subtlety of that condition meant that parents had difficulty even deciding if the child had a ‘problem’ or not. Although parents in that study had noticed subtle problems and had self-doubts in the pre-school period the full extent of the disorder did not become fully apparent until children went to school. These parents felt huge self-doubt and wondered if they were watching too much. They also felt that others did not notice what they were noticing which mitigated against validation. This contrasts with the current study in that growth and development problems were on the whole more obvious over time to parents and other people did notice too. Whereas parents’ experiences of DCD (Missiuna et al. 2006) were of a more subtle condition. The finding ‘Uncertainty – a little bit not sure’ describes a state preceding
a formal parental concern indicating that parents have assessed a child growth or development problem and appraised that it does not seem quite right or normal. As a consequence the use of an instrument to formally measure ‘parental concern’ may have limited value with parents at this stage in their appraisal.

**Parental Knowledge – ‘being and getting in the know’**

Parental concern was identified from the literature review to be a good indicator or predictor of developmental problems in children. The implication is that parents are knowledgeable about child growth and development and are able to distinguish between normal and abnormal development. The results from parents’ experiences indicated rich narratives about what they knew and found out about their child growth and development concerns. Therefore the findings in relation to parental knowledge represent the lay knowledge of these parents. As discussed in chapter two, Popay *et al.* (2003b) suggested that the rationale for studying lay knowledge is to seek explanations and meanings for the occurrences and events in daily life. It could be argued that in the context of this study, parents were faced with making sense of what was happening with their child’s growth or development. They sought explanations from family history and their previous knowledge and experience of the child. Uncertainty prevailed when they did not identify with the information sourced or their own internal cues. All the parents had ‘cognitive capacity’ as described by Mishel and Clayton (2003) by virtue of the fact that there were no impediments from illness or disability, to their information processing capacity. Cognitive capacity is an antecedent to uncertainty in the UIT and information processing is akin to sense-making which is the basis of this study.
From the findings in this study parents had, did not have, or sought knowledge about their child’s condition. They became knowledgeable about child development generally over time but it was certainly not just present or instinctual. They seemed to understand child growth and development as a dynamic entity so that if for any reasons there was a halt in the trajectory, closer examination and appraisal was prompted. This is illustrated by Jack saying that his 11 month old son is ‘not crawling’ or ‘not walking’, which was the parent’s expectation at that stage prompting a visit to the clinic for review. Many parents, especially those who had other children described how they ‘hadn’t a clue’ with their first children. Therefore gaining knowledge of parenting was a process of experiential learning for them and it was also envisaged to be a lifelong process. This mirrors De Giacomo and Fombonne’s (1998) opinion that knowledge and recognition of normal development comes with experience. Parental confidence on knowledge of child development has previously been found to be an influencing factor in accessing services (Restall and Borton 2010). Gina’s use of the term ‘our guinea pig’ to describe her first-born child points to her view of parenting as a trial and error experiment or learning on the job. Connie described how her family knowledge of autism put her ‘in the know’. She also said that she had a better grasp because of the family history and also because she was ‘not your average person’, and because of where she came from, compared to someone from a more disadvantaged area. This links very closely with the ‘them and us’ findings of Putland et al. (2011). In Putland et al.’s (2011) study, participants from a higher socio-economic area believed their health knowledge was superior to those in more deprived areas. Although similar to Connie in terms of dealing with autism, Antony and Donna’s experiences, attitudes and beliefs were very different and not necessarily explained by socio-economic class. However, the
differences between these parents supports Henderson’s (2010) view that while it is valuable to understand experiences, “lay expertise by definition is partial” and it is “idiosyncratic insofar as it reflects the experiences of one person only” (p.4-5).

Connie’s experience of autism was that her children were high functioning whereas Antony’s son had complex, challenging disabilities and as a consequence they each spoke about autism from their subjective and individualised experiences of it.

Antony and Donna developed their lay knowledge largely through sourcing research and information on the internet. For Antony, the intensive pursuit of information was preceded by denial of the existence of a problem. Intensive pursuit of information to manage uncertainty was also found by Santacroce (2003), albeit in relation to childhood illness/injury as opposed to child development, or spinal surgery (Bull and Grogan 2010), and overweight (Garrett-Wright 2011). Seeking health information online is a modern and widespread phenomenon (Ferreccio et al. 2008, Khoo et al. 2008). There is evidence that parents distinguish lay and expert knowledge but that they value the social support of the online community (Sarkadi and Bremberg 2005). Seeking information from books and pamphlets preceded the internet, for parents of children with chronic illnesses (Trollvik and Severinsson 2004) or DCD (Missiuna et al. 2006). Results in the current study indicate that while the internet was used as a resource by parents it was not always considered suitable to relieve the uncertainty related to growth or development problems. Consequently, the inherent limitations of knowledge from the internet were acknowledged and parents indicated a preference to leave the problem ‘in the hands’ of the HCPs. Some parents used the phrase ‘see what they think’ indicating a desire to approach a HCP to validate the concern, illustrating parents’ valuing of professional knowledge. This finding supports Small
et al. (2009) where uncertain Mexican-American parents believed that their HCP was the source of knowledge about appropriate size and weight for their pre-school children. Findings point to the need for further research to design educational interventions to enhance parental knowledge of child growth and development.

**Triggers to action**

Triggers to action for parents came usually from a combination of: Usual disposition – to panic or not to panic; Seeking Affirmation from Family; Seeing the Child’s Vulnerability and Time Passing. For parents in this study the culmination of these factors were eloquently described and it was almost like one little thing then just caused parents to be ‘tipped over the edge’ like Ella, or Felicity ‘freaking out’ with another new problem being noticed with her daughter. Donna described going ‘crazy’ or ‘imagining’ the concern about Oscar. It is notable that these mothers felt that they carried the burden of concern themselves, because their partners were either unworried, not involved or did not want to hear, respectively. A consequence of lack of affirmation inside the family triggered action to seek validation from a HCP outside the family.

Mishel and Clayton (2003) in the Uncertainty in Illness Theory suggest that uncertainty increases and decreases but does not necessarily reach any particular tipping or trigger point. Penrod (2007) definitively describes uncertainty as ceasing to exist when certainty is reached. It is possible that uncertainty appraised as danger becomes definite parental concern in the adaptation phase of Mishel’s (1988) model. When uncertainty is appraised as danger or a source of harm the coping activities described as focused on decreasing uncertainty could include actively seeking help but this is not described in the Uncertainty in Illness model. While it can be argued
that uncertainty is accepted as initially neutral, concern has a definite value and cannot be neutral. Parents in the current study had definitely moved beyond a neutral stance and liberally used the term concern, or worry.

Parents noticed and watched the impact on the child and acknowledged the child’s vulnerability, but it was not until others within their circle of social supports commented directly and frequently that parental action was triggered. This seemed to be the case for Siobhán, Pauline, Kim and Connie. Of these parents, Kim in particular would have held the view that she would favour letting ‘nature take its course’ and Siobhán’s husband said ‘give her (daughter) a chance’ for her balance to improve. Connie by her own admission was a ‘non-panicker’. Non-panicking was the usual disposition of these parents and they were the parents who were prepared to wait a while and be slower to act. It is possible that other people in the non-panicking parents’ circle were more apt to draw attention to the problem by just noticing the child’s problem or advocating explicitly for a more proactive response to get the child’s problem checked out. Perhaps these family and friends were familiar with the non-panicking parents’ usual disposition and believed this problem with the child was one that required action. Thomlinson (2002) also found evidence of other people being direct with parents relating to children with faltering growth. In that context it provoked questions in parents about their parenting ability. Just one child in the current study had a growth problem which was not an initial concern for her mother Denise. This case fully supported the dissonance in lay and scientific views found by Lucas et al. (2007b). The PHN made a referral on the basis of a halt to the child’s growth trajectory but Denise’s family affirmed her opinion that there was no cause for concern. Denise felt she had to ‘go along with’ the PHN’s assessment as an
expert assessment but then experienced vindication when specialist opinion at the clinic indicated that there was no clinical significance in relation to the slow height trajectory.

Family and friends were found to be a trigger for action to seek help, a finding not previously found. Their affirmation in relation to being able to see what the parent could see in the child seemed to give strength to parents to go to a HCP and express their concern. At other times they explicitly said that the parent should go and ‘check it out’. Support from family and friends were also valued by parents. This finding supports previous studies where social supports were found to reduce uncertainty and validate parental concern (Santacroce 2001). Santacroce (2003) found that parents attempted to manage uncertainty through careful evasion of social encounters but this was not found in the current study. However parents in Santacroce’s (2000) study were poor African American HIV seropositive women and were reluctant to seek information even from family because they felt so stigmatised. There was no evidence of parents experiencing stigmatising conditions in the current study.

It seems inevitable that the vulnerability of the child would be a trigger for action because parents invariably act in the best interests of dependent small children. Findings indicated that parents were cognisant of the physical and emotional impact of the growth or development problem on the child but it rarely was a sole trigger for action. This seems related to the relatively less severe growth and development problems of children in this study. It could be argued that it is easier to see how a child’s functional health status would cause parental uncertainty in children with cancer (Lin et al. 2010) compared with a child growth or development issue, because
the immediate best interests of the child in terms of health needs and treatment are
clearer. Nonetheless, the vulnerability of the child was also recognised by Missiuna
et al. (2006) in their study on children with DCD. Children in this study were being
adversely impacted in school by being teased because of limited motor skills and
poor social participation. These factors triggered parents to seek outside support.
This was echoed in the current study where Gina was keen to get her daughter’s
speech and language problem addressed before she went to school because she was
worried about others calling her ‘a baby’. The risk of a child being teased in school
was also found by Jain et al. (2001) to be a trigger for parental concern but not
necessarily action in relation to overweight children. Ahern (2000) found that
‘defensive protectionism’, a theme acknowledging the child’s vulnerability, was an
impetus for parents to continue seeking help for their children with DCD. An initial
trigger to action was not purposely identified in Ahern’s study. The desire to protect
their children stemmed from their rejection by peers but it must be acknowledged
that these were six to ten year old children. Nonetheless, the findings from the
current study point to the need for HCPs to explore parents’ perceptions of the
impact of the child growth or development concern on the child and their perceptions
regarding school readiness.

As mentioned above usual disposition was identified as a trigger for action. This
finding described panicking and not panicking as motivations or triggers for action; a
finding not found previously in studies on parental concern. However, Ellingson et
al. (2004) raised parental anxiety as a predictor to help seeking. It is possible that
increasing parental anxiety leads to panic. While these researchers found that anxiety
was a strong predictor of help-seeking among parents of children with behavioural
problems, few parents (18% of 268) actually spoke with a HCP to express their anxiety. This suggests a fundamental difference between a predictor and a trigger in that the former indicates a potential action whereas a trigger is an actual action. The current study also found in relation to usual disposition that there were parents who went to ‘check it out’ when they had a doubt of any kind. This has some resonance with the assertiveness of the parents found in Ryan and Salisbury’s (2012) study in the ‘active concern’ groups. However, the narratives included in that study were more focused on parents’ appraisal of the concern rather than the actions undertaken. Nevertheless the assertiveness as described was quite measured rather than driven by panic. Similarly, persistence was found as a personal resource influencing how parents identified and accessed services for children with developmental disabilities (Restall and Borton 2010). Whereas in another Canadian study (Shevell et al. 2001) parental insistence played only a small part of the decision to refer from primary physician to subspecialty physician. However these two latter studies while describing aspects of disposition such as persistence and insistence occurred at a later stage of accessing services.

There were parents in the current study that had concerns yet did not act quickly on them. Some of these parents described themselves as the non-panickers and seemed quite happy to wait and see if the problem improved. This finding is similar to that of Skeat et al.’s (2010) study where although parental concern was a strong predictor of seeking help in pre-school children with speech and language concerns yet there were substantial numbers of parents with concerns who had delayed seeking help. This finding has important clinical implications in terms of the need to assess parents’ usual disposition to identify those who may be more likely to adopt ‘a wait
and see’ approach. This type of assessment may require research over a period of time.

The passing of time influenced parents’ actions but they did not describe it as such. Instead parents alluded to time passing when they spoke about how fast their children were growing or developing. It is widely acknowledged that young children grow and develop quickly. Caring for young children is demanding for parents and sometimes parents are forced to confront or assess what is happening. Donna captured this best when she spoke about being aware of Oscar’s developmental problems but when her older daughter commented in the car about him losing his words she said children sometimes are good to point out the obvious and she had been too busy to see. It is almost like time passing is variable in speed and parents sometimes may think they have more time to deal with an issue and then a deadline like starting school looms.

Triggers to action as a combination of factors were not previously found in studies relating to parental concern. Given the complexity of child growth and development it is unsurprising that triggers to action would be a multifaceted theme influenced by the broad determinants of health. Therefore this finding is very important in terms of understanding what influences parents to decide to go and get their child’s problem checked out. In terms of implications for practice it implies that there is need for HCPs to adopt a bio-psycho-social model of care to ensure the needs of the family are appropriately assessed.
Getting the child’s problem checked out

Getting the child’s problem checked out is a superordinate theme identified in the current study. It originated from three subordinate themes which were: ‘Just check it out’; ‘Getting into the health system -public or private’; and ‘In the hands of the professionals’. Parents in the current study were focused on a problem which was a concern about child growth or development, they acted by making a decision to seek help and this entailed an interpersonal contact with a selected health care professional. The elements: problem focused; intentional or planned action; and interpersonal interaction with a selected HCP are all attributes, and thus support Cornally and McCarthy’s (2011b) concept analysis of help-seeking behaviour. They support the concept of help seeking in a general way in that all are present. However universal child health services were the context of the current study and what differs from Cornally and McCarthy’s (2011b) conceptualisation of help-seeking is that parents in the current study were seeking help for a dependant. The support of ‘Getting the child’s problem checked out’ for the concept of help-seeking behaviour is useful as a broader description or conceptualisation of what parents are doing and may have potential uses in terms of measurement in future potential research.

There were some parents who were uncertain and purposively went to a HCP and expressed the concern about the child growth or development problem. There were others who were attending a routine health check at a clinic or a HCP was doing a home visit and they had decided that the problem was on their ‘list of questions’ or on their ‘agenda’ to ask. The child growth or development concern was verbalised by ‘just mentioned in passing’ or some other oblique way. The nuanced way they went about expressing the concern to seek help was ‘tentative’; broadly similar to the
‘vague non-specific question’ that a parent may ask of a professional described by Ahern (2000). Parents in Ahern’s (2000) study were conceptualised as on ‘a journey’ to seek help for their six to ten year old children with dyspraxia. The vague non-specific question took the form of a statement rather than a question and described what the child was doing such as “she keeps falling over” in the context of the child’s motor skills. Although parents in the current study did not describe what they said, but rather how they said it, it does support Ahern’s (2000) findings about a ‘vague’ statement approach rather than a question. The vague approach taken by parents’ in Ahern’s (2000) study was not validated by teachers and HCPs who dismissed the concern. Parents learnt to become more specific about their child’s problems, even to the extent of proffering the coordination disorder diagnosis and making specific requests for intervention. This suggests that parents learn to use scientific or professional language in order to be heard and have their concerns validated. Parents in Ahern’s (2000) study were at the end of the long journey and had attended many health and educational professionals hoping they would recognise their child’s subtle developmental problem. The parents most similar to these in the current study were Andrew and Donna in terms of the length and stress of the journey. Further research is needed with parents like these to understand how they adapt their language in order to be heard.

Problem recognition was found in the current study to be challenging and parents experiences were dominated by uncertainty as previously discussed. Although they were uncertain they appraised that there ‘there is something wrong’ with their child. Problem recognition was found to be greater than that described by Cornally and McCarthy (2011b) which may be accounted for by the fact that the concept analysis
was largely focused on illness rather than health and ADHD was the only brief reference to child development issues.

The current findings clearly indicated that parents’ initial assessments of their child’s problem were ‘inside’ the home and that accessing help from a HCP were from ‘outside’. This finding suggests that parents exhaust all possibilities of making sense of concern and uncertainty within their own lay circle before going ‘outside’, that is to a HCP, to do so. Williams (2007 p.285) suggested that a divide between the ‘confines of the family’ and ‘sources outside the family’ exists and equated it with competing responsibilities of mothering; a finding not evident from mother’s experiences in the current study. Broadhurst (2007) found that parents described very clear moral boundaries between inside (within the family circle) and outside (formal/professional) help for personal or domestic problems in families. Where inside help was unavailable, parents perceived they had no-one to turn to. However, it should be borne in mind that Broadhurst (2007) explored parental help-seeking in the context of child welfare as distinct from child health and as a consequence parents may have had more fears of being scrutinised by authority figures. Broadhurst (2007) believed her findings were not unexpected as targeted child welfare services can be perceived as different and potentially stigmatising. In contrast, universally delivered child health services are widely perceived to be non-stigmatising.

Parents in the current study described selecting or accessing a specific service or HCP in order to articulate the child growth or development concern. This suggests a planned behaviour to select a service as described by both Cornally and McCarthy (2011b) and Eiraldi et al. (2006) in the context of help seeking. In terms of how they
selected a service parents in the current study described past and present experiences with private and public services which influenced their choices. Experiences with services were recounted in terms of initial access and on-going involvement. In terms of access some parents may have had a medical card that entitled them to free GP care and although not elicited, the cost of a GP visit was a definite factor in choosing which service to access for at least one parent, Muriel. Lack of knowledge on how to access universal public services affected some parents to the extent of causing distress about trying to negotiate their way through bureaucracy. This indicates a need for services to be better ‘signposted’ such that the direction to be taken by parents to access a HCP is clearly marked. Problems in relation to accessing services in the HSE are widely acknowledged. Mostly parents had an existing professional relationship with a PHN or GP that influenced who they approached first for help. These experiences were both positive and negative. Ultimately they were seeking accessible services provided by trusted professionals who would listen to them, validate their concerns and either reassure them or help them manage the problem. There was no evidence from parents’ narratives that their concerns were formally or systematically elicited using instruments but this is unsurprising as screening instruments are not recommended in Ireland (Health Service Executive 2005a).

Home visits by a PHN were seen by some parents as more conducive to expressing a concern but not the case for other mothers. In terms of valuing home over clinic visits one of the parents in the current study (Noelle) said that going to the clinic ‘felt like an appointment’. The reluctance to raise the issue of concern with the GP may be because going to the doctor has been described as quite a formal, structured endeavour, from making an appointment, to involvement in the main ‘business’ of
eliciting and imparting information (Francis and Hester 2004). Francis and Hester (2004) acknowledged the imbalance between patient and doctor related both to the illness and physical examination. GP consultations differ substantially from well-baby or other drop-in clinics run by PHNs. These PHN clinics are quite informal and the interaction is structured around parents’ needs, usually for advice related to childcare. Other parents spoke about the problem as ‘not being enough to go the GP’ or that the problem was not expressed while attending the GP. Kim suggested that it is better if one goes to the GP with a particular focus or agenda. Felicity said she didn’t feel rushed and had time to talk at the PHN clinic, both implying time constraints at GP surgeries. Noelle also raised the point about concentrating on the child of concern rather than raising a concern relating to another child. GP appointment systems and short consultations were previously found (Ryan and Salisbury 2012, Sayal et al. 2010, Williams 2007) to be barriers to parents expressing a concern. Therefore creating time and space for parents to be able to express their concerns is important and HCPs need to be flexible in terms of scheduling consultations.

There were suggestions from some parents that GPs were more focused and expert in relation to illness and it was considered that the public health system comprising PHNs and public health doctors had more interest and expertise in child growth and development. In the current study parents described situations where the problem was not severe enough to the go the GP and GP consultations were more valued in terms of dealing with acute illness. Sayal (2010) in a study involving children with ADHD similarly found parents sometimes felt there were problems which were not within the remit of the GP, that is, not explicitly ‘health’ conditions such as emotional or behavioural issues. Ehrmann Feldman et al. (2005) found that having a
regular physician contributed to recognition of neuro-motor problems. However this may have been more to do with continuity and the existence of a therapeutic relationship.

When parents went to a GP in the current study they concentrated their efforts on one child with one problem. However GPs in a number of cases were not picking up the concern cues, possibly indicating that they were not sensitive to the subtle way they were expressed by parents. This left these parents feeling ‘let down’ by the experience. Felicity explained that this was because ‘you go’ and ‘ask them something and they say no that is fine they will grow out of it’ and she (her eight month old daughter) ‘quite clearly’ did not because everyone since then said the plagiocephaly was ‘very severe’. This description captures not only the upset about the lack of validation of the concern but also upset that the GP was wrong in his clinical assessment. The GP’s response resulted in Felicity not doing anything about her concerns for about four months. A similar finding from Missiuna et al. (2006) identified that some parents who did not receive affirmation from others put their concerns ‘on the back burner’ (p.5). Non validation of parental concerns was also found in relation to neuro-motor problems (Ehrmann Feldman et al. 2005) or ‘not being heard’ in relation to faltering weight (Thomlinson 2002).

Feeling ‘let down’ by HCPs was found previously with parents of children subsequently diagnosed as autistic (Ryan and Salisbury 2012). In another study one parent was angry about the delay and inappropriate reassurance and had assumed the ‘doctor knew best’ (Watson et al. 2006). Ultimately there was a lack of trust and confidence previously found in healthcare providers (Sayal et al. 2010, Watson et al.
A variety of positive, negative, helpful and dismissive responses from HCPs was also found in a study of parents of overweight adolescents (Edmunds 2005). In Edmunds’ (2005) study, some parents queried an underlying medical cause with their GP and those who reported positive experiences felt they had been listened to and their concerns validated. Where concerns were dismissed, GPs cited the developmental nature of adolescent weight gain. This was a little like saying the children will ‘grow out of it’, a response that so upset Felicity and other parents likewise. This response may have been due to a deficit in expert knowledge about child growth and development and a genuine desire to reassure parents. However Magnuson and Hergils (2000) stated that “a desire to allay anxiety may be detrimental when parental fears are well founded” (p. 291). Lay knowledge and lay concerns need to be acknowledged and fully assessed by HCPs.

A notable element of Antony and Donna’s experience is the divergence between their lay knowledge and the so-called expert knowledge of their GP when they went to get the child’s problem checked out. This supports William’s (2007) finding that scientific truths were held to be more valid than parental experience. In Donna’s opinion particularly, her two year old Oscar’s regression in language ability and his repetitive behaviour with the wheels of the toy car were indicators of cause for serious concern. However the GP did not attend to their concerns about Oscar and engaged by suppressing certain information, in what Glascoe (2002) described as ‘passive expectancies’ or the ‘flu model’ of development. This is “characterised by temporizing (meaning ‘wait and see’), a developmental or behavioural problem with watchful waiting”, but without interventions such as suggestions for stimulation, assessing development or making referrals (Glascoe 2002 p.89). A wait and see
approach was also found elsewhere in relation to medical assessment of developmental problems (Poon et al. 2010) and ‘watchful waiting’ in relation to hearing problems (Lok et al. 2012). Parents expect far more of GPs and if it is appropriate to ‘wait and see’ then it should be handled in a far more parent-centred proactive way as previously suggested (Shevell et al. 2001).

Some parents experienced frustrations in accessing information and publicly funded services. Antony and Donna in particular felt the need of someone to help them coordinate it all: “we need someone that would say listen there is few different things you can do…” [Donna 1036]. This occurred because they were accessing separate private services to address each of Oscar’s individual development problems and felt lost. Previous research found that not only were relationships with trusted individuals vital to expressing the concern but also to ‘system navigation’ (Restall and Borton 2010) or clarifying the ‘service journey’ (Cowley et al. 2013). Antony and Donna eventually met and developed a relationship with a PHN in the public system and navigation to early intervention occurred. But at that stage their past experiences left them feeling it was ‘all (a) kind of a mess’. The many challenges Antony and Donna faced were similar to the parents in Missiuna et al.’s (2006) study. Those parents struggled to such an extent and undertook such convoluted loops to access services for their children who were eventually diagnosed with DCD that the theme was labelled as ‘negotiating the maze’.

The findings in relation to parents’ appraisal of the PHN service were that on the whole PHNs were seen by parents as accessible, knowledgeable and professional. It is possible that the PHN was seen by parents as the first step on the professional
help-seeking ladder after formulating that the problem could no longer be dealt with inside the family. There was evidence in the current study of some efforts by parents at managing the problem themselves. For example, Gina and her husband worked very hard to help their daughter with her speech articulation problem before they went to get help from their PHN. She explained how they were “trying to get this thing of putting the teeth down onto the lip” to help with her articulation. This supports to a certain extent ‘failed self-management’ as described by Cornally and McCarthy (2011b) in the context of help-seeking. This describes the actions taken by individual who try to manage their health problem on their own and only make a ‘decision to act’ to seek help when that fails. However most parents in the current study just hoped the problem would improve which would have been more likely with child development than an illness related problem. Parents would not have tried managing the problem themselves for their children, possibly because they did not know how to go about it. For example Noelle “was shown exactly what physiotherapy to do” and worked on that for her daughter’s positional talipes present at birth. Other parents such as Siobhan designed their own interventions after going for help. She went to indoor children’s play environments such as Monkey Maze and Supernova to “build up her steps” and assist with the balance problem. These findings indicate how keen parents are to assist their children achieve their full developmental potential and as such would be amenable to learning more about stimulating their child’s growth and development.

Parent experiences of a therapeutic relationship with their PHN were mostly very trusting in the current study. They spoke of them by name, indicating that they had known them over a period of time, such as “from the fourth day” [Meg] after the
baby was born, and had found them to be helpful. Knowing the PHN was considered
important by Kim and she spoke about knowing when her PHN Breda “is on” (on
duty) but “wouldn’t really know them (the other PHNs) up there” at the health centre.
To Kim this was conducive for her to “run up to her” to ask about anything, an
opinion that was echoed by other parents (Gina, Muriel, Noelle, Felicity, Ella,
Sonya). The value that parents place on a therapeutic relationship with a PHN is
supported consistently in a recently published review of health visiting research
(Cowley et al. 2013). As a result of parents going to the PHN in the current study,
their uncertainties were reduced or their concerns validated. These parents felt
supported by their PHNs. This finding supports previous findings in relation to
support from HCPs (Santacroce 2000, Watson et al. 2006). Some parents of children
who were failing to thrive were found to feel nurtured by HCPs (Thomlinson 2002).
Mishel and Clayton (2003) suggested that ‘structure providers’ such as HCPs with
their ‘Credible authority’ could reduce or increase uncertainty by their input in the
antecedent phase prior to appraisal. The current findings did not support this as it was
only after the parents had appraised the stimuli frame as a danger that the parent
approached the HCP. The Uncertainty in Illness Theory originated in the context of
illness and as a consequence HCPs may be more immediately present and answer
questions relating to the illness in an on-going fashion. This differs to parents in a
community setting who may well have experienced the uncertainty and its appraisal
inside the family before venturing out to seek support and uncertainty reduction from
a HCP at a later stage. Parents such as Connie who described not having a good
relationship with their PHN acknowledged this as her experience and she knew of
other parents experiences that were different. She also acknowledged the impact of a
previous bad experience. This mirrored the perceptions of parents in Watson et al.’s
(2006) study of striving for a therapeutic relationship varied by their former health care system experience. Findings in relation to the value of the therapeutic relationship to parents highlight the need for such relationships to be fostered and enhanced from an educational and practice perspective.

**Strengths and Limitations**

The strength of this study is the new insights found regarding the experiences of parents about child growth and development which add new knowledge relevant to effective preventative child health services. Using Interpretative Phenomenological Analysis permitted an idiographic, inductive and interrogative exploration of the phenomena adding to the body of knowledge on parental concern. New findings were identified which have implications for: policy governing preventative child health services in Ireland; the educational preparation of Public Health Nurses; clinical practice with children and their parents; and future research to build on the current findings.

As with any study there were also limitations. The purposeful sample of parents selected could have been a highly motivated group. As such they may have differed from those parents who may have had a concern but who did not express it. The sample varied in terms of gender, type of growth and development delay and *per se* may have been too heterogeneous for IPA, which favours homogenous samples. Furthermore the sample varied in terms of the timeframe since they first noticed concern to being interviewed. This may have contributed to problems of recall in providing retrospective accounts. Interviews were relatively short by IPA standards, because of childcare demands on parents. Nonetheless, great depth of data were achieved which contributed to the depth of findings. In this study I sought to
understand the experiences of these parents in-context but it is necessary to
acknowledge that this knowledge was generated through interpretations based on my
existing knowledge and the theoretical perspectives reviewed.
Conclusion

Eliciting and attending to parental concern is a fundamental component of HCPs’ work with parents in the context of preventative child health services. Early identification and intervention with growth and developmental delay is an effective means of improving health and well-being outcomes for children and their families. Parents play an essential role in monitoring their child’s growth and development and bringing any deviations in growth or development to the early attention of HCPs for review and possible intervention. Most children with growth and development problems have delayed identification of them until after they start school. Evidence from the literature review indicates that parents either fail, or are reticent to express their concern and HCPs do not routinely or effectively elicit concern from parents. There is limited empirical evidence examining parents’ experiences of child growth and development concerns. Parents were found to have difficulties accessing services and trusted HCPs to express concern. No study specifically sought to understand parents’ experiences of concern in terms of how they made sense of it. Conceptual and theoretical literature provided some useful insights in relation to how parents respond in illness situations but lacked consideration of child growth and development scenarios. Therefore the aim of this study was to understand how parents make sense of child growth or development concerns and an IPA study was designed to address the knowledge and methodological gap.

Two contextual themes were found which captured how parents described The Concern – ‘telling it as it is’ and their experiences of being Referred on. ‘The Concern ‘telling it as it is’ captured the lay knowledge and terms parents used to try and articulate or name the concern so that they could talk about it to their family first
and later to a HCP. Another new finding was that there was growth or development concern about a child other than the ‘child of concern’ indicting the need for clinical assessments to incorporate more than the child of concern. The waiting period after being ‘Referred on’ was found to be stressful, supporting other studies and was found to be a time where parents appreciated as much feedback from HCPs as possible.

Four superordinate themes were found Uncertainty – ‘a little bit not sure’; Parental Knowledge – ‘being and getting in the know’; Triggers to action and Getting the child’s problem checked out. Uncertainty – ‘a little bit not sure’ captured how parents made sense of the child’s growth and development problems. In addition to watching, comparing and wondering which supports previous findings, parents also assessed whether their child could ‘do other things’ or if something particular could have caused the growth or development problem. These latter new findings show how parents, particularly mothers, grapple with unfamiliar cues in the complex and multifaceted nature of child growth and development in their efforts to make sense of what is happening with their child. Fathers’ experiences are limited in the current study and deserve further research. Findings also revealed new knowledge about the emotional impact of uncertainty regarding parents’ concerns about their child’s growth and development. It has important implications for HCPs in relation to listening to parents without minimising their lay knowledge; acknowledge the emotional impact of uncertainty; and to identify the strategies they use in order to probe their concerns. It should not be assumed that if a parent has no concerns that they are not experiencing uncertainties or that they are sure about their child’s growth or development.
Parents were influenced by *Parental Knowledge* – ‘being and getting in the know’ which aided their sense making. What they knew from their experience or personal history and sought from elsewhere may have assisted in answering some of their questions but raised more, so it did not always relieve the uncertainty. The internet was used by parents but it was not always considered suitable to relieve the uncertainty related to child growth and development concerns. Parents indicated that they valued professional knowledge but it was evident that they needed and wanted more knowledge on child growth and development, highlighting implications for parent education and research.

*Triggers to action* were found to be caused by rising uncertainty from a confluence of factors which were: the vulnerability of the child; other people affirming and noticing; parents’ usual disposition of dealing with problems and time passing. Sometimes the combination of these factors meant that parents perceived that the problem was not causing undue harm, and for others immediate action was required. The finding in relation to the confluence of *Triggers to action* had not previously been found and direct the need for HCPs to conduct broad assessments that include: parents’ usual disposition; the impact on the child, incorporating parents perception of their readiness for school; and the availability and opinions of social supports.

After parents exhausted all possibilities of making sense of the concern they were described as ‘Getting the child’s problem checked out’. They went ‘outside’ the family to express their concerns to HCPs. Some parents reported difficulties in identifying and accessing appropriate services highlighting the need for improved
signposting. The factors that assisted expressing a parental concern were therapeutic relationships with HCPs, particularly PHNs, who were known, trusted, accessible and knowledgeable. Parental expression of growth and development concerns about their child was found to be complex and nuanced. Accordingly concerns may not be readily understood by HCPs implying a need to reappraise how parental concern is elicited and attended to in order to promote early referral and intervention of children who may have growth and development problems.

As a consequence of the new knowledge found in this study it is important to note the fundamental role of the parent in the support of child welfare and development and the importance of harnessing the parent as a resource within a public health context. Parental concern was found to be a complex phenomenon which includes uncertainty and therefore a single question “do you have a concern?” included on checklist assessments is likely to be insufficient in elucidating the challenges parents face. Exploring parental concern is a skilled process requiring active questioning and listening techniques and is a fundamental aspect of the public health nurse role. These factors strengthen the importance or universal service provision within preventative child health services in Ireland. In conclusion recommendations are made which address the findings from this study relevant to practice, policy research and education.

**Recommendations**

**Clinical practice**

In relation to clinical practice it is recommended that community HCPs:
• Engage in effective therapeutic relationships and work participatively with parents to promote the timely expression of parental concern.

• Ensure that public health nursing assessments take account of the broad determinants of health as well as focusing on individual, family and community as clients. Adopting a broad public health nursing approach to assessment will create an awareness of the need to consider: all children in the family; parents’ usual disposition in dealing with child health problems; the availability and input of family supports and the need for signposting of community services.

• In the event of HCP uncertainty about the existence of a growth or developmental problem and a need to monitor for a while, then this should be handled appropriately by fully assessing development, making suggestions for stimulation, or making referrals for specialist assessment.

• Provide feedback and involve parents as much as possible in structured interventions during the process of referral and waiting for the outcome.

Research

In relation to research it is recommended that:

• In depth exploration of parents’ use of lay language in the context of preventative child health services be researched.

• Help-seeking in relation to uncertainty about child growth or development be measured in representative samples of parents who, have and have not, expressed a concern to a HCP, to identify the extent of unmet need.

• An intervention study is designed to test child growth and development education packages for parents and their impact on expressing concern.
• Instruments such as the PEDs should be tested with an Irish sample to assess their potential utility as an adjunct to care in assisting HCPs elicit parental concern.

• Fathers’ experiences in relation child growth and development concerns are explored.

Policy

In relation to health policy it is recommended that:

• The delivery of a high quality, equitable, effective child health services is prioritised and on-going service evaluation is required to ensure they are achieving their goal of improving child health.

• Child health services need to be adequately signposted so that parents are fully aware of how to access HCPs in the event of not being identified in the universal service.

• There is anecdotal evidence that the developmental assessments for children at 18 to 24 months and 3 and quarter to three and a half years delivered by PHNs are not being prioritised for both current economic reasons and the precedence afforded to curative care. The study findings indicate that continuity of access to PHNs in the period from 18 month to four years is critical to parents expressing concerns about their children. Therefore it is recommended that all core assessments contained within the CHSSHP programme in Ireland need to be fully implemented.

• Referral rates to specialist services need to be monitored in terms of identifying unacceptable delays for children and their parents.

Education

In the context of education it is recommended that:
The educational preparation of community Health Care Professionals such as public health nurses and doctors and GPs needs to be re-evaluated in the context of the findings.

All relevant HCPs should undertake standardised education programmes of preventative child health underpinned by best available evidence.

HCPs need specific education regarding the complex strategies that parents use to appraise uncertainty in relation their child’s growth and development and how they communicate their concerns, to ensure that parents’ lay knowledge is correctly elicited and attended to.


Appendices
Appendix 1. Written permission from DPHNs to access clinical sites.

Dear Helen,

Thank you for your email and attached Research Proposal.

As previously discussed I am willing to support this study and permit you contacting Public Health Nurses within North East C C after you have received ethical approval.

Kind regards

Triona Scully, A/DPHN
On behalf of Colm Williams, A/DPHN
Abalfoyle House,
Georgesquay
Cashel

From: Gwendalyn (Administrative Officer)
Send: 12 April 2012 16:49
To: Triona Scully (Director of Public Health Nursing)
Subject: FW: Seeking your support for child health research relevant to Public Health Nursing

Dear Helen,

I would be supportive of this worthy research and would enable you to approach participants once ethical approval is obtained

Regards,
Vivien

From: McKelvey, Helen (Nursing Studies) [helen.mckelvey@ucc.ie]
Send: 19 April 2012 15:50
To: Vivien Hans (Director of Public Health Nursing)
Subject: FW: Seeking your support for child health research relevant to Public Health Nursing

Dear Vivien,

I am proposing to carry out research entitled "An exploration of the process by which parents of children referred to second tier child development services experience uncertainty in relation to child growth and development concerns." This study will be part fulfilment of a Doctorate in Nursing Practice under the supervision of Professor Eileen Savage here in the School of Nursing and Midwifery, UCC. Professor Savage is keen for me to interview some parents at an early stage before I refine the literature to ensure I don’t deviate too far from the data and participants. This will facilitate seeking ethical approval at the next committee meeting. The submission date for the next meeting is the 19th of July. As you are both gatekeepers to the study sites firstly I need to get your permission to approach participants in writing/email outlining your support etc., which I would do by Thursday the 12th April. I have attached a draft of what is proposed thus far and will be working on the next few days, I will be in the office on next Tuesday if that works for you.

Best regards

Marguerite Harford (Clinical Officer)

Connect to social network to show profile photos and activity updates of your colleagues in Outlook. Click here to add network.
Appendix 2 Ethical approval

COISTE ETICE UM THAIGHDE CLINICIUL
Clinical Research Ethics Committee

11th May 2012
Professor Eileen Savage
College Lecturer
School of Nursing & Midwifery
Brookfield Health Sciences Complex
University College Cork
College Road
Cork

Re: An exploration of the process by which parents of children referred to second tier community child health services experience child growth and development concerns.

Dear Professor Savage

Expected approval is granted to carry out the above study in:
- Cork North Lee, South Lee and West Cork Local Health Office Areas.

The following documents were approved:
- Application Form
- Study Protocol dated April 2012
- Insurance Certificate
- Interview Guide

We note that the co-investigator involved in this study will be:
- Helen Mulcahy.

Yours sincerely

Dr Michael Hyland
Chairman
Clinical Research Ethics Committee of the Cork Teaching Hospitals

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognized 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 3. Cover letter to potential participants

Catherine McAuley School of Nursing & Midwifery
Brookfield Health Sciences Complex
University College Cork,
College Rd.
Cork.

Date

Re. Research project exploring parents’ experiences of expressing a concern about their child’s growth or development prompting onward referral.

Dear parent,

I am undertaking the above study as part of a Doctorate degree at University College Cork. I propose to interview parents to develop an understanding about their experiences of expressing child growth and development concerns. It is hoped that this study will be of benefit to parents in similar circumstances in the future and also help health professionals such as Doctors and Public Health Nurses in delivering quality child health services. Your assistance and participation would be greatly appreciated.

I have enclosed an information leaflet explaining exactly what is involved in the study and I hope you will take the time to read it. Thank you for your assistance.

Yours sincerely,

___________________________
Helen Mulcahy,
Nurse researcher
Appendix 4. Study Information Leaflet for Parents.
This leaflet is to provide you with information about a study being carried out to explore the experiences of parents who have been referred for further investigation because they have expressed a concern about their child’s growth or development.

What is the study about?
The study is seeking to develop a better understanding about how parents think about and act when they have concerns about their child’s growth and development.

What is involved in this study for you?
Your name was selected from the pre-school referrals to second tier community child health services maintained by the Director of Public Health Nursing in your area. Your public health nurse was asked to give you this letter and information leaflet and ask if you would be willing to be contacted by the researcher Helen Mulcahy. With your agreement Helen Mulcahy will contact you by telephone, answer any further questions and ask if you are still willing to take part. Arrangements will be made to meet at a location that suits you or your own home, if more convenient, and sign a form consenting to be interviewed. This informal interview about your experiences will take about 30 to 60 minutes and will be taped on a digital audio-recorder.

Will the information I give be kept confidential?
The information you will give will be kept confidential. Your name and address will not included on the interview record. A code number will be used instead of your name. When the report is written up it will not be possible for others to identify any participants.

Who else will be taking part in this study?
Approximately 14 other parents will be taking part.

What are the benefits of the study?
By identifying how parents think and respond to concerns about their child’s growth and development it is hoped that the information will be used to help them express this to healthcare providers and perhaps help healthcare providers ask questions in a better way around the complex area of child development. It is also hoped that the results of this study could be used to teach student PHNs and other health care professionals caring for families who have similar experiences to yours.

Do I have to take part in the study?
There is no obligation to take part in the study. Even if you agree at first, you have the right to withdraw at any time.

Does the researcher have permission to carry out this study?
Yes. The researcher has received ethical approval for this study from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. The researcher was granted permission by the Director of public health Nursing in your area to approach Public Health Nurses to identify potential parents for the study.

Thank you for taking the time to read this leaflet. If you have any further questions you may contact Helen Mulcahy at 021 4901638 or 087 9587685
Appendix 5. Consent by subject for participation in research protocol

Section A

Protocol Number __________________________ Patient Name: __________________________

Title of Protocol: An exploration of the process by which parents of children referred to second tier child developmental services experience child growth and development concerns

Investigator Directing Research: Helen Mulcahy Phone: 021 4901638

You are being asked to participate in a research study. Nurses at University College Cork study the nature of health and attempt to develop improved methods of helping people to promote and maintain health. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

Section B

I. NATURE AND DURATION OF PROCEDURE(S):
The aim of the study is to explore the experiences parents have when they have a child referred for further investigation in a community child health clinic because they expressed a concern about their child’s growth or development. Your name was selected from the referral form made by your public health nurse to the community child health clinic. Contact was made with you by the researcher only after you had indicated your agreement to take part in the study. When Helen Mulcahy contacted you by telephone, she gave you an opportunity to ask any further questions and checked that you are still willing to take part. Arrangements were made with you to meet somewhere that suits you and for this consent form to be signed. After written consent you will be interviewed about your experiences, which will take about 30 to 60 minutes. This interview will be taped on a digital audio-recorder. The researcher may contact you later when she is doing the analysis to check for your opinion.

II. POTENTIAL RISKS AND BENEFITS:
There are no physical risks to taking part in this study. You may become upset while being interviewed because you are being interviewed at a worrying time in your life. However you may also find it helpful to have an opportunity to talk about your worries. Your experiences may be useful in assisting other parents in the future and help healthcare professionals provide quality, responsive services.

III. POSSIBLE ALTERNATIVES:
You may choose not to participate in this study

Section C

AGREEMENT TO CONSENT

The research project has been fully explained to me. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted in Cork Local health office areas. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the nurse listed above. If I have further queries concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork.

After reading the entire consent form, if you have no further questions about giving consent,
please sign where indicated.

Nurse Researcher: ____________________________

Signature of Subject, Parent or Guardian

Witness: ____________________________

Date: ____________

Time: ____________

(Circle)

AM   PM
Appendix 6 Interview Schedule

Background details (for completion by researcher gleaned from interview)

1. Name _______________________________
2. HSE LHO Site _______________________
3. Length of interview _______________________
4. Relationship to child: Mother [     ], father [     ].
5. Parental (Interviewee) Age Group _______________________
6. Living with? _______________________
7. Mother's Occupation _______________________
8. Father's Occupation _______________________
9. Number of children in Family _______________________
10. Age of child at interview i.e. Current age of child in years and months: _______________________
11. Child gender _______________________
12. Age of child when concern first expressed _______________________
13. Reason for referral to second tier services (in parents own words)

Questions regarding parental experiences

I’m interested in hearing about your experiences of noticing something the matter with (child’s name) growth or development. Can you tell me about that?

Probe - What did you first notice in your child that indicated to you that you needed to seek further help?

Did you seek further information on this anywhere?

Probe – where did you get this information?

Was there a period of time between first noticing something and actually saying it out loud to someone?

Probe - How long was this period of time?

Can you tell me more about that?

Probe – why do you think that happened?

Who did you first say anything about it to?

Probe - How did they respond to you?

Probe – How did you find that approach?

What was going through your head at the time you were concerned?

How did you go about getting a referral for your child to be seen?

In hindsight is there anything you would have done differently?

Probe - is there anything your PHN or doctor could have done differently?

Can you tell me about your feelings now?

Thank you very much for sharing your experiences with me.
Appendix 7 Convention for transcription of audio files.

Page setup
Portrait
Margins 3cm on right and left, all others 2.5 cm.
Single spacing
Font size 12

Transcript headings
File name
Duration
Date
Interviewer = I
Participant = P and indicate which one by the number of the interview e.g. P.3

Transcript
- Verbatim transcript of narrative but no need to capture every confirmatory ‘yes’ or ‘OK’ used by the interviewer.
- Capitals for Names
- Use original names for this version (researcher will change them later)
- [...] for missing text
- Best guess e.g. [bribery?] for words you are not sure about
- Every speaker receives his/her own paragraph. There is no need for a blank line between the speakers.
- Discontinuation of sentences or abrupt stops within a word are indicated by a colon and slash :/
- Punctuation is polished up in favour of legibility e.g. insert commas, full stops and question marks as appropriate.
- A short drop of the voice or an ambiguous intonation is indicated by a full stop rather than a comma.
- Pauses are indicated by the word pause in parentheses (pause)
- Words that are emphasised by the speaker are inserted in capitals e.g. ABSOLUTELY NOT
- Disturbances are noted in brackets e.g. (phone ringing)
- Emotional, non-verbal utterances (of both the interviewee and the interviewer) that support or elucidate a statement (such as laughter, giggling or sighs) are transcribed in brackets e.g. (laughs)
- Insert line numbers from start of interview
### Appendix 9 Gantt chart

<table>
<thead>
<tr>
<th>Tasks</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading to prepare for first supervision</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal meetings with first supervisor</td>
<td>14th</td>
<td>11th</td>
<td>5th,</td>
</tr>
<tr>
<td>Subtask: 14th</td>
<td></td>
<td>21st</td>
<td>11th</td>
</tr>
<tr>
<td>Subtask: 4th</td>
<td></td>
<td>2nd</td>
<td>3rd</td>
</tr>
<tr>
<td>Subtask: 11th</td>
<td></td>
<td>10th</td>
<td>26th</td>
</tr>
<tr>
<td>Subtask: 5th</td>
<td></td>
<td>25th</td>
<td>29th</td>
</tr>
<tr>
<td>Subtask: 21st</td>
<td></td>
<td>10th</td>
<td>17th</td>
</tr>
<tr>
<td>Subtask: 11th</td>
<td></td>
<td>5th</td>
<td>23rd</td>
</tr>
<tr>
<td>Subtask: 2nd</td>
<td></td>
<td>6th</td>
<td>6th</td>
</tr>
<tr>
<td>Submit draft material to 2nd supervisor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reviewing the literature</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing literature chapters</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing methods section</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Submit for Ethical approval</td>
<td>18th</td>
<td>8th</td>
<td></td>
</tr>
<tr>
<td>Data collection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data Analysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mid-term Review</td>
<td></td>
<td></td>
<td>6th</td>
</tr>
<tr>
<td>Writing up literature review</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing up methods</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing up findings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing up discussion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collate and print thesis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Submission</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Penult.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Final</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Viva</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissemination of findings - conference in Cork, Graz, Galway, etc</td>
<td></td>
<td></td>
<td>2nd</td>
</tr>
<tr>
<td>SONM, prepare paper for publication, etc</td>
<td></td>
<td></td>
<td>3rd</td>
</tr>
</tbody>
</table>

Helen Mulcahy DN Gantt Chart
Appendix 10 Screenshot of analysis log from NVivo
**Appendix 12 Table of themes for Uncertainty – “a little bit not sure”**

**UNCERTAINTY - “A LITTLE BIT NOT SURE”**

<table>
<thead>
<tr>
<th><strong>Appraising the concern</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Watching for a while</strong></td>
<td>“...like I was kinda looking but, it’s a case that she was too young really, they were saying the bridge hadn’t formed, so at this stage she was too young to notice so” [Meg 13-16]</td>
</tr>
<tr>
<td></td>
<td>“No I was kind of watching for a while. I was saying is it my imagination or is there something here you know ...” [Pattie 41-44]</td>
</tr>
<tr>
<td><strong>Making comparisons – “Barometer”</strong></td>
<td>“Well I have ten nieces and nephews and I would have used them as a barometer... it’s hard to judge as they are all different...” [Denise 89-93]</td>
</tr>
<tr>
<td></td>
<td>“...I look at other babies to see if they have exactly the same size of their eyes or not (laughs)” [Sonya 242-243]</td>
</tr>
<tr>
<td><strong>Assessing child doing other things</strong></td>
<td>“...we knew she was running and she was jumping and she was skipping and she was doing everything that she should be doing...” [Noelle 68-70]</td>
</tr>
<tr>
<td></td>
<td>“Anyway she's ahead of her game in lots of other ways” [Denise 110]</td>
</tr>
<tr>
<td><strong>Puzzling – “Is there something wrong”</strong></td>
<td>“I do feel there is an issue there ...I don’t know what it is” [Muriel 190-192]</td>
</tr>
<tr>
<td></td>
<td>“I am wondering kind of, I don’t know” [Siobhán 262]</td>
</tr>
<tr>
<td></td>
<td>“Because I suppose I did worry like I was a little bit stressed about it ... so I was kind of just thinking ‘oh God could there be something more’” [Felicity 198]</td>
</tr>
<tr>
<td><strong>Wondering about the cause</strong></td>
<td>“...so I was thinking maybe is it craving a little attention for Mammy” [Muriel 93]</td>
</tr>
<tr>
<td></td>
<td>“But I am thinking then would it be the walker like I use to put her into the walker at the start and I was thinking would it have been the walker that would have caused it but you just don’t know” [Siobhán 96-98]</td>
</tr>
</tbody>
</table>
### PARENTAL KNOWLEDGE – BEING AND GETTING IN THE KNOW

#### Being ‘in the know’

“...It’s there in the family...”[Ella 17]

“…it wasn’t obvious to us we had no clue, sure we didn’t know anything about it” [Connie 233-234]

“so I guess when I first had him I knew no different” [Muriel 201-202]

#### Seeking information –‘just Google’

“Online there was a few things ...I was reading online that people were actually sent to physiotherapy for those kind of things” [Sonya 268-269]

“...I used to be on the internet saying you know how to stop it (behavioural problem) and then I used to see on Sky there you know Living Channels you know the Fairy Godmother used to come around. Did you see the Baby Whisperer? I used to 'series link' that and I used to watch that? ...That’s it, she (Super Nanny) was great, like it’s all learning though” [Siobhán 467-473]

---

27 The Baby Whisperer is a fifteen parts Discovery Home and Health TV series presented by Tracy Hogg (The Baby Whisperer).

28 Supernanny is a reality TV programme which originated in the United Kingdom about parents struggling with their children’s behaviour.
## Appendix 14: Table of themes for Triggers to action

### TRIGGERS TO ACTION

#### Usual Disposition

“*We do believe in letting nature take its course. They are very young and I think they can catch up at their own time you know.*” [Kim 148-149]

“*Yeah I am that kind of a person if I see something I would follow up I can’t just let it go I have to make sure it is fine before :/ (laughs)*” [Sonya 195-196]

“*You know what I mean and I am not a panicker at all. I don’t panic about things*” [Felicity 353-354]

#### Affirmation from family

“…*He (partner) said we’re probably better off getting it checked out, he felt she was just getting tired as well*” [Muriel 101-104]

“*Certainly my sisters, one was a nurse, my child-minder(were agreeing with me) (ex-partner) doesn’t have much involvement…he’s a bit under the radar*” [Denise 107-108]

#### Seeing the child’s vulnerability

#### Impact on the child

“…*he really had to fight to look straight, now he is much better now though, but it was tough for him in the beginning*” [Sonya 61-62]

#### Others noticing the problem

“…*I suppose it wasn’t a nice thing to be looking at*” [Ella 742]

“My Aunt and my sister would say ‘Ally you have fallen again’, and I would notice it but she probably wouldn’t take any notice like, ‘you have fallen again upsy daisy, upsy daisy’ you know and you would be conscious of it” [Siobhán 117-122]

#### Time passing

“I must have been (mulling over that) because …*I had it in my head I will wait until the two years and I will go to the two year check-up*” [Connie 98-80]

“I said we will have to get this checked before she goes into school” [Felicity 398-400]
### Appendix 15 Table of themes for Getting child’s problem checked out

<table>
<thead>
<tr>
<th>GETTING CHILD’S PROBLEM CHECKED OUT</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Just check it out</strong></td>
<td></td>
</tr>
<tr>
<td>Better safe than sorry</td>
<td>“... I went to health centre in (place name) and asked” [Edwina 67]</td>
</tr>
<tr>
<td></td>
<td>“I rang Nadia (PHN) and Nadia said oh bring her in” [Siobhán 52-53]</td>
</tr>
<tr>
<td>Mentioned in passing</td>
<td>“So it was probably around when I started noticing it and I just went and mentioned it (laughs) ...But I didn’t seek, I didn’t really:.No” [Sonya 107-115]</td>
</tr>
<tr>
<td></td>
<td>“so I did mention it to Inez (PHN) again saying listen I really don’t know if there is anything wrong but I am afraid to ignore it just in case...” [Muriel 26-31]</td>
</tr>
<tr>
<td>Getting into the health system, public or private</td>
<td>“I found the call-ups very thorough with the check at 10 months then Dr.X and then at two years. Y’know I wouldn’t have expected anymore” [Meg 136-139]</td>
</tr>
<tr>
<td></td>
<td>“…we have huge experience and any time we ask any questions we are definitely met with all the info we need, we are given literature and there is great contacts I have to admit... It is a fantastic service” [Noelle 146-148]</td>
</tr>
<tr>
<td></td>
<td>“(Department of Education) were fantastic they had no problem comparing to HSE it was a different story, different world” [Antony 197-200]</td>
</tr>
<tr>
<td>In the hands of the professionals</td>
<td></td>
</tr>
<tr>
<td>Professional validation</td>
<td>“I went to my GP and she was the same so I felt like I am looking for something but that doesn’t really exist because everyone you know thinks maybe I am crazy I don’t know” (laughs) [Donna 478-480].</td>
</tr>
<tr>
<td></td>
<td>“But I just I suppose with everything I need professional reassurance” [Ella 718]</td>
</tr>
<tr>
<td>Therapeutic Relationships</td>
<td>“Yes, (PHN helpful) very good” [Edwina 69]</td>
</tr>
<tr>
<td></td>
<td>“Yes it is nice having a (PHN) to say things to but I don’t think I’d be overly bothered if it was somebody else…it’s (continuity) nice you’d know the person what they’re like” [Meg 167-169]</td>
</tr>
<tr>
<td></td>
<td>“I mean he is a very good GP… I suppose like he was very blasé about it” [Felicity 124]</td>
</tr>
</tbody>
</table>